Repositioning Speech Language Pathology practices: Engaging with family and community narratives to evolve communication supports for neurodivergent children

by

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Plagiarism Declaration

I, Prianka Parusnath, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being or is to be submitted for another degree in this or any other university.

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Date 23 October 2024

Dedication

For Mila, for Ollie, for Tate, for Yusuf, for Aliza. For all the children who have come before you and all those who will come after you, thank you for showing me the way.

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1.1. Introduction

I hate being called a Speech-Language Therapist. Definitely not the opening lines you would expect to read in a thesis into which I have poured my blood, sweat, tears and hope. But it's true. The expectation and weight that comes with **Speech** feels like a constant battle against the heart of what I really do. It is a label I feel I am constantly fighting against, a betrayal for every family who pleads for information about when their child will talk. Speech is a gold standard I have not adhered to for a very long time when Communication is key. If we are truly championing our profession, Communication should be at our core. It has been for me. This project has felt like a combination of raging against the profession, a comfort to myself as a professional, and an intervention for a career I care so much about but that doesn't always see when it needs help. It has been filled with unlearning, relearning, mourning, grief and hope. I feel so privileged to be able to take you on this journey with me.

1.2. Experiences of Exclusion that Shaped Me: My Weekend News

We all have our own backgrounds and experiences and below you will find a short insight into an experience that has shaped me. I am Prianka. I am South African, as my family have been generations before me. If Africa is my roots, then my Indian heritage is the water that gives them life. I was born into a world that looked down on my brown skin and though the walls of Apartheid crumbled around me when I was just four years old, the repercussions have been felt, rippling through my whole life. This my weekends news.

When I was in the Grade 1, we started a writing class called Weekend News. In this period, we wrote down memorable things we did over the weekend and presented them to the class. One weekend, I went to the movies with my grandfather, Dada[1]. Being the tender age of seven, I did not know then how to spell "dada" and asked the adult known to guide me, my teacher, for advice on how to resolve this. What I did not expect, was to be greeted with a blank stare when doing so. The word was unfamiliar to her and at the time, Dada was all I'd known — I couldn't give any more information to her.

[1] The Hindi word for grandfather.

I didn't actually know he was my grandparent because he was never referred to as such. At pick up, my parents eventually explained the situation and the matter was cleared up — my teacher learnt that there were different terms for grandparents, and I stopped referring to my grandfather as dada for a very long time. On this day, I walked away with three realisations: 1) That my parents were my heroes for showing up for me, 2) that teachers don't always know it all, and 3) that people, and who they are to us, mean everything.

1.3. My New Learning

I moved to New Zealand in February of 2023 and it has been a weird and wonderful experience. In my reflection over my time here, I am unravelling the notion of a "first world" country. First World, seems to just mean Western World. I see many parallels between New Zealand and South Africa in terms of systemic issues such as poverty, inequality, racism and colonisation. Both countries have painful histories, the scars of which most of us still bare today.

The West is better able to hide these issues by performative policies and clever use of indigenous languages woven into the everyday but these problems still exist glaringly and obviously — even from under the rug they have been swept under. From a speech therapy perspective, both countries are experiencing a shortage of Speech Language Therapists (SLTs), both countries have communities that struggle to access our services and both countries are still trying to figure out how to serve communities without the lens of colonialism. It is true that Australia and New Zealand have the luxury of standardised assessments that have been normed for Australian and New Zealand populations but these assessments do not include any sort of cultural lens or inclusion of indigenous voices. How do you standardise such a vibrant and varied population? So really, how standardised are they and for whom?

1.4. The Danger of Expectation

There has been a growing discomfort for me around SLT practice and the rules that govern it. As a society, we talk a lot about how damaging social media can be in creating certain perceptions. And this is true for Speech Therapy as well. The internet is a great superpower, but it can be terribly misleading. Any time you Google Speech Therapy, it is the same images that come up (Appendix A). It's almost always a woman with a child, sitting at a table and demonstrating some kind of mouth movement or pointing to a letter.

I believe that the women in therapy rooms you see on Google, and websites of professional associations, are harmful stereotypes and set unrealistic expectations of what we should be doing as therapists. In the role I have taken up here in New Zealand, there is *immense* pressure on fixing, normalising, and making better. I haven't had to practice in the field of Speech Sound Disorders for the past 10 years, in South Africa I was immersed in an environment where communication was my focus, where neurodiversity was the norm, and my sole focus was around Alternative and Augmentative Communication (AAC). In my new role, it's a free for all and I am a "Jack of all SLP trades" and a master of none. I find myself existentially wondering why we do it at all? I hear the anguish in parents' voices in initial conversations where they are stressed because their child can't say "s" or "k" or "d". At the same time, parents and teachers are so concerned about the fact that this little child is saying "bampire" instead of "vampire" that they don't hear that a five-year-old can you tell you that vampires don't show up in photographs or that they are a burned by the sun or that they are scared of garlic. What a story – it is a joy to see them come alive!

While this is a valid concern for each parent and the journey they are on, sometimes the deficit becomes overpowering and we lose sight of who children are outside of that deficit. The therapy model in New Zealand is supposed to be working with the adults around the child to empower caregivers and ensure therapy is happening everywhere. But it feels like an uphill battle when Google is saying something different. Google, tradition, history, is saying SLTs will fix them. But is that what they need?

1.5. A Little Girl Called Moo

For the last six years, I have been immersed in an environment that has focused my therapeutic lens on children with disabilities. In this time, I have come to know and understand these children who are able to find ways to thrive in a neurotypical world despite the challenges they are constantly facing. The ongoing battle and refusal to accept being stuck in a box or branded by a diagnosis. This time was the most influential in helping me switch between my therapeutic and human lenses. Moo was the affectionate nickname of one of the students in my care. She was a little wildflower of a girl, a non-speaking girl with autism, who had fire in her soul. She started with us when she was just 18 months old and newly diagnosed. In the six years I had known her, she blossomed in ways we were too scared to even dream of. She was what someone could classify as moderately autistic but to us, she was our fierce, free and beloved motivator.

She has since moved overseas with her family as they felt that South Africa could not handle her fire, and that the world she was growing in was too conventional to accept her ways. Her meltdowns drew too many stares, her echolalia created too much confusion for a community who couldn't understand what was wrong with this "normal"-looking child. Outings became debilitating and, slowly but surely, I watched this family retreat into our safety net and then find the courage to make a move that they thought would give their family a chance at a more fulfilled life.

I thought of others who did not have the opportunity to do the same and how change was desperately needed. They left our shores and though we are thousands of kilometres apart, we remain connected through the wonder of technology and our shared experiences. It always made me wonder what would happen if we lived in a world where we recognised the child first and not the label. If we had a community that raised her, and children like her, up. If maybe, we were not pathologists first.

Working with families who have children with disabilities has been one of my biggest moments of unlearning thus far. Coming to realise that I was not always the expert; that parents' understanding of all non-verbal communication surpassed my own; that families were the dictionaries that would help me understand their loved ones. I was just one person in a much larger web of connection which allowed me to break down barriers that I hadn't realised I had built.

My time at Khanyisa Developmental Centre allowed me to partner with families in order to create communicative opportunities and build meaningful foundations for language learning. These families have been a range of typical nuclear families, single parental households holding it all together, matriarchal grandmothers deeply invested in their grandchildren's wellbeing, the aunties who step in for mothers no longer with them. Regardless of who they are, rather than prescribe a management plan as the professional, the families and I created the best "detective" partnerships, working together to create understanding and find a path for our children. Shifting this power balance meant that collaboration was the centre of our intervention and collaboration meant holistic input into the life of this family. To me, I feel pride at taking up the mantle of co-learner, co-creator and co-therapist, with the realisation that we are always in this together and that we are always better together.

1.6. The Journey

At the beginning of my PhD journey, one of my co-supervisors asked me a question as a prompt to help me choose a topic. This question has subsequently driven my entire research process. The question was: "What keeps you up at night?". It was the beginning of my own journey of discomfort within my profession. For many years I worked at a Developmental Centre for children with a variety of disabilities. This place grew my passion for working with alternative communication. What kept me up night was how often I put the burden of Alternative and Augmentative Communication (AAC) on families when communication is a team sport. I teach Makaton[2] (a form of key word signing) and I facilitate core boards and then these tools that I love in a different environment can become alien and isolating. They are almost immediately and automatically "othered" outside of the therapy room.

And then it occurred to me that maybe as Speech Language Therapists (SLTs) we are not working in the right place. This thought pattern started forming from the stories that I've heard over the course of my career. Individual Educational Development Plans were a staple at this Centre I worked at. They were a safe space for families and a powerful place of introspection for me. Here I heard stories of families trying to allow their child to ask a question at a supermarket using AAC and receiving strange looks from other customers. I heard stories of a child's request for more cake at party go unnoticed because their Makaton wasn't seen over the clamouring of seven other five-year-olds who also desperately needed sugar. This perspective was vital in re-evaluating the tools I had been using as a therapist. It made me realise that communication is three things and it needs three things: Community, Inclusion and Belonging — concepts we will explore in the next few chapters. At its heart, communication connects us all if you have the "right" tools to do so. I have had the privilege of listening to so many stories that inspire, break moulds, smash boundaries and make me rethink everything I've ever known as a therapist.

[2] It is worth noting that Makaton has come under fire for its appropriation of Sign Language and in the cases mentioned in this study, the Makaton signs were used for communication support and not as a replacement for Sign Language.

1.7 The Aims that Guide

At its core, the aim of this project was guided by three main aims. The first is to explore family narratives of acceptance, belonging and inclusion within families and community spaces. The second, to loo k at how stories of community engagement can evolve future practice for Speech Language Pathologists (SLPs) in community spaces when working with a special needs population. And the third is to propose a practice framework to reposition future community-informed SLP practices.

1.8. Conclusion

Over the next few chapters, I will take you on this journey with me through my research. I will set the scene for the study, lay the ground work of the literature, explain the aims and objectives in more depth in the methodology, and then pull you into the research so you can experience some of these stories for yourself. It is my hope that at the end of this thesis you will be as moved as I have been by the strength, bravery and vulnerability of everybody who has been courageous enough to share. The study explores the intersectionality of context, politics, culture, communication, community, inclusion and speech therapy.

Chapter 2: Study Focus

2.1. Introduction

This chapter will set the scene of the study by explaining the research problem and why this focus is essential. It will set the scene of the challenges that South Africa faces in particular and speak to the wider Majority World context within the framework of SLP[3] practise. It will explore the complex web of intersectionality that threads through disability. Along the way, there are text boxes that contain my reflections on the theory being discussed. A large part of this thesis has been propelled by storytelling, and it would be a disservice to the project to not include the author's voice that has much to contribute for a project so personal.

2.2. Study Context: Recognising the Rainbow (The Triumphs and Failures of a Rainbow Nation)

Here at the edge of the world in South Africa, there are 12 official languages that reflect the diversity and dynamism of our country. There are mountains, forests, savannahs, mangroves, and sparkling oceans as far as the eye can see. We are resilient, we are multifaceted, and we love a good game of Rugby. We have come a long way since facing the vilest of adversity and we have a long way to go. South Africa is considered the "Rainbow Nation" an astounding prism of race, culture, religion, history, language, and community (Mdlalo et al., 2019). Each thread of this rainbow more nuanced than the last. The ideology of the Rainbow Nation was born near the end of Apartheid as a tool to promote cultural identity while still uniting a fractured nation (Myambo, 2010).

As a "melting pot", we would all have dissolved and disappeared into a murky brown. While there are some countries in the Minority World that prefer this brand of multiculturalism, the rainbow became a symbol of individuality and togetherness where each culture can hold their own while still emanating the light of *ubuntu*.

In theory, it was the kind of nation building that we needed; but in reality, with our colonial roots and a country that was monopolised by white owned and run majority, it was a far cry from reality (Holmes, 2015; le Roux, 2022; van der berg, 2007; Walker, 2005). It was a project that didn't actually change anything about our situation back then, but worked toward changing how we saw it, allowing for small strides toward reconciliation (Myambo, 2010). My first-grade experience I spoke about earlier was in 1997, just three years after the end of apartheid.

[3] Throughout this thesis, SLP and SLT will be used interchangeably

The wounds were still raw, fresh, and open and most professionals (such as Speech-Language Therapists) were still white, which meant that for the moment, stories like mine were not the exception. That early in post-1994 South Africa, there was no expectation of cultural evolution, effortful understanding, or learning; it was largely reparations and moving forward. But now, there definitely is — the expectation to reframe what it means to be a multicultural and proudly African nation, to find our true place in the world guided by our own set of values that are viewed through our own lens (Mashau, 2018). It is a painstaking process of undoing our colonial roots and finding our place in the world once unleashed from them (King et al., 2014; Ndlovu-Gatsheni & Chimbati, 2013).

2.3. The Elephant in the (Therapy) Room

Though South Africa fought hard for its democracy, it was not a fight that was truly won, the ramifications of which are still seen today. The aftershocks of apartheid and its politics are felt by people of colour, particularly by black South Africans who are impacted by the past inequality and poverty that has rippled into our present day (Harsha Kathard & Pillay, 2013). One may wonder how this affects the profession but, in all honesty, trying to separate politics from the profession would be like trying to acknowledge hot but not cold, embracing darkness without light.

In South Africa, communication disorders are most commonly experienced by black South Africans who continue to live in conditions that echo apartheid — poverty, limited access to healthcare, exposure to drugs, violence and numerous other social disadvantages (Kathard & Pillay, 2013). It is a vicious cycle. Even in a country with 12 official languages, therapy is predominantly provided in English, with Afrikaans being a close second — a language of the oppressor still so present 20 years later (Murungi, 2015; Pillay et al., 2020; Seabi et al., 2014). Most of the assessments and interventions used are in English and based on American or European concepts and norms, creating barriers again and again for those outside that elite sphere (Mdlalo et al., 2019). Communication can so easily become discrimination. By this logic, therapy can all too easily become discrimination (Bogart & Dunn, 2019; Chisale, 2020; O'Connell, 2022).

For Black South Africans who often have to grab on to the bottom rungs of the access ladder, therapy approaches like these are the proverbial snakes on the gameboard, pushing them back to the lowest rung with a constant fight for appropriate service, cultural recognition and linguistic variety (Mophosho, 2018). Some have been fighting for so long now that they are tired of doing so.

Author Reflection: In my final year of university, there was a study in progress looking at speech sound acquisition in isiZulu speaking children. And there we went again, trying to quantify, pigeonhole and staunch the flow of a language that moves so fluidly, with its own rhythm and current that carries it because our Eurocentric lens told us that we needed norms and structure to help that river flow. There is such artistry in a click that echoes in a mother tongue and the nuance of it is lost when we dissect it for the sake of trying to find the normal.

When we look at any member of this population experiencing an impairment against the backdrop of these larger pre-existing issues, it seems like an impossible fight. But there is hope. That hope falls on us as SLPs to change our colonial-rooted, Eurocentric practice. Perhaps it is time for us to embrace *ubuntu*. When one considers the ratio of trained SLPs to population, South African SLPs are unable meet the need of the people who require our services (Staley et al., 2022). As of 2018, the ratio of South African SLPs to patients was 1:18000 (Pillay et al., 2020, Health Professions Council of South Africa, 2018). A sobering statistic. And that's why a shift toward community practice has so much potential for us going forward.

To support communication is to create connection and that is difficult to do shut away in rooms. Working with communities is a humble step toward forming a work force that is literally on the ground, making sure the ripples of our knowledge spreads widely, that our therapy reaches further and our presence is felt deeply. These experiences often lead to withdrawal from activities as a family and decreased participation in social events (Hurst, 2003). For these families, their community gets smaller and smaller and more secluded leading to feelings of exclusion and isolation (Antonsich, 2010b). They say it takes a village to raise a child, but when that village doesn't rise to the occasion or stigmatises that child, the burden is placed on the family. It can be a very lonely and daunting road.

Currently these issues around access and alternative communication support are areas that are being improved upon in many countries around the world; with communication supports being introduced in public spaces and therapy moving into community (McCurtin & O'Connor, 2020). As such, I have come to experience frustration with the limitations of my practice and for the people of South Africa when I see how SLP input is sorely needed within communities to advocate for these individuals and their families in order to create accepting and inclusive spaces. Growing up with *ubuntu* as a way of being, we have an immeasurable advantage of trying to implement this type of shift.

Author Reflection: We have all heard many a tale of companies who failed to innovate, evolve, adapt and ultimately who failed to find their place in a changing world. I love who we are as a profession and what we stand for, but I feel as though this shift is necessary for us to stay relevant. And for that, I believe we start with stories, we listen to, envision and understand the bigger picture and we support the children, their family *and* their community. We knock those traditional four walls down and we work toward creating meaningful partnerships with those around us, those around the family.

As SLPs in South Africa we have a long way to go fighting against societal norms and navigating the complex intersectionality between disability, race, gender, a painful history, and our diverse population (Cho et al., 2013; Coaston, 2019; Nash, 2011). Very simply put, intersectionality speaks to our ability as humans to be many things all at once (Reitzel et al., 2021). A person cannot and should not be examined by their individual elements of identity. Oftentimes, disability is seen as the whole picture without professionals considering the landscape of a life — of lived experiences (O'Connor & Pettigrew, 2016). This in turn affects an individual's access and agency (Wickenden, 2023). For example, if they belong to multiple disadvantaged groups, their experience of exclusion might be exacerbated (Cho et al., 2013; Moodley & Graham, 2015). Intersectionality adds a critical lens to seeing a person as more than just their diagnosis. The lens moves disability away from being purely biological and explores the fluidity of context, and environment on the continuum of a persons experience (Ben-Moshe & Magaña, 2014).

Since the term Intersectionality was coined by Kimberlé Crenshaw in 1981, the concept has been applied to various fields in order to broaden perspectives and closely examine people's lived experiences. It exposed how one-dimensional thinking not only hinders knowledge production but affects law making, policy creation, education, and social justice as well (Cho et al., 2013; Reitzel et al., 2021).

These areas that are the grass roots of society are all impacted and how we grow is what we choose to nurture (Carbado et al., 2013). Recent research emphasises how larger political and ethical paradigms such as racism, ableism and capitalism have been ignored as key aspects of intersectionality in the Northern neurodiversity movement (Nair et al., 2024).

Author Reflection: When I think of my early years of practice, I think of that perfect room with a table in one corner and a foam mat in the other. A shelf of books and a cupboard of toys. Four walls that scream order, structure, conformity, and detachment. In my toolbox I had the usual suspects: *The Clinical Evaluation of Language Fundamentals*, a Mr Potato Head, some blocks and the forever favourite, a fishing game. And every time a child would mistake that red wagon for a cart or something other than the expected answer written in black and white, my confidence would drain out of me and doubts would take its place. Because this child in front me, who was being raised by his grandparents, and loved helping in the kitchen and played soccer at school and who would look out for his little sister at church on a Sunday — he was so much more than the sum of his standard score.

Chapter 3: Conceptual Framework: The Web of Community, Community and Belonging

3.1. Introduction

This chapter aims to detail the interwoven and complex conceptual framework that underpins the study and carries it forward. Communication and Community are central to it all. In a country like South Africa, it is difficult to separate communication, disability, inclusion and community as these concepts often are inextricably linked through history, politics, culture, economics and a variety of other factors. To look at one, means to look at them all. In order to practice in a way that best serves those who need it, there needs to be a practice shift. Instead of just one single-minded and limited focused practice lens, the profession needs a kaleidoscope. It needs a lens nuanced enough to see the bigger picture and capture the intricacies that make it up.

The constant swirling, churning, rearranging of every piece of this conceptual framework will explain the inequality, injustice, origins of power hierarchies and the exclusion that exists today for individuals with disability, more than the current SLP lens is capable of doing.

3.2 Speech Therapy and Communication

Communication is a process of joint meaning making that connects people to the world and to each other (Balandin & Hines, 2011; Trembath et al., 2022; Wylie et al., 2017). Emphasis on the joint. Communication is a skill that wouldn't exist if we all lived in a vacuum (Abrahams et al., 2022).

> Author Reflection: I'm sure it feels like something of a fever dream but just recently we lived through a pandemic. And in the midst of social distancing and lock downs and months of separation, the lifeline that many of us had was communication and connection. Imagine if we didn't have that? The isolation and exclusion of not being able to Zoom call a parent or WhatsApp a friend. Though we were so far apart, there was a concerted effort being made to stay connected and communication was the thread that bound us all.

Multiple Speech Language Therapy Associations, including the American Speech Language and Hearing Association and Speech Pathology Australia, define communication as the process of exchanging ideas and information involving both understanding and expression. They each go on to further elaborate that Social Communication is the "how" and the "why" of using language to interact with other people (Donovan et al., 2006). It is a strange distinction given that the majority of, if not all, communication takes place in relation to another person (Friedman & McNamara, 2018; Mandak & Light, 2018; Wickenden, 2011). One could go so far as to say that communication exists as the bridge for interacting with the world around us (Hourcade et al., 2004; Mdlalo et al., 2019; Trembath et al., 2022). As SLTs you probably wouldn't think so, as one Google search is enough to show a variety of (almost always) white women sitting at a table with a child using some kind of hand gesture or alphabet to help the child with their talking (Appendix A). This is still the perception today, that SLTs work on speech, talking, words, verbal language. But this couldn't be further from the truth.

Author Reflection: It took me a while, but it made me realise that I was not the expert when it came to how families wanted to live their lives. Parents knew every small gesture, every facial expression, and every varying cry. They were actually the communication experts, the dictionaries, and interpreters and secret keepers of their children. I was a looming presence under the guise of being the professional that was assessing and judging. It takes time to shift that kind of power imbalance but a good starting point

Providing intervention for individuals with a disability is central to the profession (Balandin & Hines, 2011; Bickenbach, 2014; St. Pierre & St. Pierre, 2018). Disability in itself is a complex web that is influenced by economics, politics, culture and a very long history of discrimination and exclusion (De Sas Kropiwnicki et al., 2014; Jasmine, 2022). In South Africa it is not just apartheid but ableism that is pervasive and heavily influences concepts of "standardised" and "norms" that are vital to the profession (Bogart & Dunn, 2019; O'Connor & Pettigrew, 2016). There is a notion that disability is created by the impairment that a person experiences, but disability can also be caused by the environment people live in and by the interactions they have with people in them (Etieyibo, 2022; Ngubane-Mokiwa, 2018; Schweik, 2011). When the focus is on disability it only highlights the problems that the individual experiences, but when the lens shifts to inclusion, there is increased capacity to focus on solutions on how to achieve it (Robinson et al., 2020; Slater et al., 2020).

Disability Studies aim to unpack these concepts while also building momentum with the justice movement for individuals who have disabilities (Kasnitz & Block, 2013; Solinger et al., 2008). It is an embarrassment to humanity that those who already experience challenges have to fight that much harder for basic human rights such as the right to employment, the right to be included and the right to a quality of life (Berghs, 2017a; Darling, 2013b, 2013a; Sépulchre, 2020; Threats, 2010).

This discussion is a rabbit hole, deep and winding, and seemingly endless. To cover the entirety of the disability movement from its conception would require a new thesis. For the purposes of this study, the most salient points that will be covered are the importance of the lens with which we view disability inequality, the exclusion that individuals with disabilities have experienced in the Majority World, and where and how speech language therapy plays a role when it comes to disability support and service provision.

3.3. The Priority of Speech and the Origins of Augmentative and Alternative Communication

For the longest time, speech and oral language have been heralded as the gold standard for how we communicate (Bondy, 2019; Donaldson et al., 2023; Henner & Robinson, 2023; Light & McNaughton, 2012; Myers, 2007). It is a viewpoint SLTs are uniquely positioned to change. For many years, almost the entire history of the profession, spoken language has been the prime target of early intervention when it comes to disabilities (Donaldson et al., 2023; Kasnitz & Block, 2013). And yet, even after this focus of intervention, a large population of children end up being “minimally verbal” (Rose et al., 2016; Trembath et al., 2022).

Augmentative and Alternative Communication (AAC) was introduced in the early 70s as a support for individuals with complex communication needs, almost exclusively for those with non-speaking autism (Bondy, 2019; Donaldson et al., 2023; Mandak & Light, 2018). The thought behind it was to provide a way for individuals with little to no speech to communicate with others, access education, maintain relationships and engage with the world around them (Donaldson et al., 2023; Smidt & Pebdani, 2023; Steinberg Lowe et al., 2024)The field has made significant scientific and technological advances since it’s recognition in the field as a support system for communication (Donaldson et al., 2023; Hourcade et al., 2004; Ogletree & Harn, 2001).

However, Augmentative and Alternative Communication, was the last resort after a deluge of speech-related interventions (K. L. Anderson et al., 2015; Kasnitz & Block, 2013; Rose et al., 2016). This focus on speech as the benchmark for communication has resulted in a seesaw of inequality that places those with communication impairments below oral language users. In this way, stereotyping, stigmatising and consciously or unconsciously discriminating against those who cannot "speak" in the traditional sense when it comes to education, employment and general expectation around quality of life (Ngubane-Mokiwa, 2018; O'Connell, 2022).

Even the label itself sets this communication apart with the use of the word "alternative". The language used around disability and communication is extremely powerful and yet the field is entrenched in language that looks down on everything other than speech as other (Henner & Robinson, 2023). Society has become fixed on idea of "normality".

Author Reflection: When I graduated, I thought AAC was the last area I would end up working in. The thought of being responsible for someone's entire communication system felt paralysing. It seemed so vast and it seemed too important and I wasn't sure how to condense the expanse that is our everyday speech into a finite number of symbols. After many years of practice I came around to realise that this perspective in itself was damaging to my clinical outlook and to my client families as well. This view alone was incredibly reductive and minimised any alternative form of communication. Not to mention the constant pushback I received from parents who were not ready to give up on speech. Nine times out of ten, the initial question in any Individual Education Development Plan meeting (IEDP) was "when will my child talk?". For the longest time speech and oral language have been heralded as the gold standard for how we communicate and it is a viewpoint we are uniquely positioned to change.

Over the last few years, the data of those with lived experiences of disability shows that, above any of the physical challenges of a disorder or diagnosis, communication impairment often remains one of the biggest challenges and source of pain (Kasnitz & Block, 2013; Leonard, 2012; Murphy et al., 2018). Though this is experienced differently by each individual, there seems to be a consensus around this issue of communication. People who experience communication impairment have limited access to a variety of communication partners which hinders their ability to participate in even the most basic of life events, such as talking on the phone or asking for help in a public place (Donaldson et al., 2023; Hamm & Mirenda, 2006; Kahonde, 2023; Politano, 2015).

For many parents who have children with disabilities, abandoning their AAC system seems like the simplest solution because the barriers seemed too great (Anderson et al., 2015). Barriers included lack of long term SLT support and insufficient training on how to use the device (Berenguer et al., 2022). The additional stress of adjusting to this new way of communicating, along with the time demands on learning how to use a device, contribute to the feeling of abandonment (De Bortoli et al., 2014). This is staggering when you consider 50 – 60% of children with intellectual and developmental disabilities are non-speaking (Donaldson et al., 2023). There is a need to explore alternative methods of implementation that share this load and create a shared experience rather than burdening families.

The journey of becoming an AAC user is quite personal — it is the creation of a unique communication system in a manner that is accessible for each individual. There has been criticism in the field of SLT from families and AAC users who have reported that professionals do not take into account communication needs of each person but rather push their agenda of nouns, verbs and preprogrammed sentences they think might be of use (Balandin & Hines, 2011). What this community is telling the profession is that communication happens with a variety of people in a variety of environments and not just in a therapy room (Balandin & Hines, 2011; Gerteisen, 2015; Halder, 2017; Wickenden, 2011). It is time that the profession listened.

3.4. A Practice Shift in a South African context

As specialist therapists, SLTs are a finite resource in the public sector and gatekept even more so by the cost of accessing us in a private capacity (Butler, 2019). For a country like South Africa where there is a history of racial and economic injustice, access is heavily skewed toward the white middle and upper class (Abrahams, 2019; Pillay & Kathard, 2018; Staley et al., 2022).

There are numerous challenges that exist when it comes to effectively engaging communities that include power imbalances, divergent perspectives, a lack of trust between communities and outsiders, and a lack of respect by professionals for a community's cultural climate (Israel et al., 1998). Additionally, the majority of SLPs are English speaking, white females who don't often represent the communities they work with ethnically, culturally or linguistically (Litosseliti & Leadbeater, 2013).

This is especially true of the South African context. Although the profession has been undergoing transformation in South Africa for the last 20 years, the reform of academics, curriculum and policy has been a slow journey relative to growth of other professions in the medical field (Abrahams et al., 2019; Moonsamy et al., 2017; Staley et al., 2021, 2022).

As a profession that has had close to 100 years of practice within the country, SLP practice still has a long way to go to respectfully and appropriately be able to serve the population of South Africa. There is much that has been overlooked, that continues to be overlooked, when providing services to particular groups, most significantly black South Africans. Providing effective and efficient SLP support is a multi-faceted process that needs to consider the individual as a whole: gender, race, culture, economic background, geography, attitudes, beliefs and past experiences.

Furthermore, when working with diverse populations, there is a large amount of unlearning and deconstruction of practice that needs to take place in order to support individuals holistically. One of the most meaningful ways to do this is by engaging with the individuals who require access to these services as well as the communities who support them in their daily lives.

3.5. Supporting Communication Disability: Past, Present and Future

3.5.1. Disability Studies through the ages

In recent years, disability in the Western World has most commonly been viewed through a deficit lens where it is seen as a barrier, tragedy, or impairment (Grech, 2015; Hernández-Saca et al., 2018; Hiranandani, 2019; Schneidert et al., 2003). Research in disability studies has largely been driven by the Global North and has only reinforced this viewpoint (Berghs, 2017a). Disability has become something to hide, discard, and exclude (Antonsich, 2010a; Chisale, 2020; Robinson et al., 2020). It wasn't always this way. Disability in African history, has been celebrated and revered, it has been seen as a link to the spirit world, a gift from the ancestors (Kozma, 2006; Lawal, 2011; Ojok & Musenze, 2019). Even in ancient Greek mythologies, people with disabilities could be gods, they were often granted gifts of enhanced senses or other increased abilities as a result of their disabilities (Halder, 2017). The Norse God Odin who exchanged his eye for wisdom and the Greek God Hephaestus, master craftsman and artisan were heralded for their skills and abilities (Graham, 2019).

The focus was not on their loss but what they had gained. Their counsel was sought, their opinions were respected and their knowledge was valued. Narratives like these now are few and far between (Ngubane-Mokiwa, 2018; Roman & Sonn, 2017).

Through colonisation, there has been a shift away from the humanism of these ancient ways (Precious, 2017). In the present day, disability carries stigma that can lead to low self-esteem, depression, financial difficulties, and ultimately social exclusion (Trani et al., 2020).

There have been multiple models through which to view those with disabilities: the medical model which aims to problematise difference; the charity model that divides and infantilises; the social model that turns the lens toward communities; and the rights based model that puts up a fight (Bickenbach, 2014; Bogart & Dunn, 2019; Hurst, 2003). No model is perfect or without its flaws. Speech therapy is rooted in the medical model and, as a caring profession, has had a dalliance with the charity model (Amponsah-bediako, 2013; Levitt, 2017; Wylie et al., 2013).

But the one thing that all these models have in common is their origins in the North (Ned, 2022). The loudest voices in the room have been those of the Global North (Grech, 2015; Meekosha, 2011; Ned, 2022). Research in disability studies has largely been driven and dominated by these voices which has only reinforced this viewpoint of deficit, barrier, and burden (Berghs, 2017a).

Few studies have managed to capture the complex intersectionality that individuals with disabilities experience in the Global South (Meekosha, 2011; Pillay & Kathard, 2018; Wickenden, 2013). In developing countries, persons with disabilities are excluded based on a variety of barriers including historical, psychological, structural and sociocultural limitations (Antonsich, 2010a; Halder et al., 2017; Pinilla-Roncancio, 2015).

Within the field of speech therapy, disability is almost always framed with a viewpoint of a communication impairment in a vacuum (Bogart & Dunn, 2019; Chouinard, 2014; Law et al., 2005; Wickenden, 2013). At university practitioners are taught about the importance of AAC but aren't necessarily taught that an occupational therapist and physiotherapist will be vital to its access (Mandak & Light, 2018; Threats, 2010). Practitioners aren't taught that while they are the gateway into communication, parents hold the key. Or look holistically at who a person might communicate with, the places they frequent, and the activities they might be a part of. When disability is explored within the profession, it is not looked at widely enough to see anything other than the tools needed to support communication.

Eventually, research needs to go beyond the boundaries of the profession's knowledge base in order to grow and learn (Dirth & Adams, 2019; Etieyibo, 2022; Meekosha, 2011). The Therefore disability theories are important to engage with when considering transformation and repositioning of practice. Particularly from the standpoint of inclusion, these theories should be everything to SLPs as professionals, but it is only one small piece if it is even considered at all.

3.5.2 Neurodiversity and Ableism

Neurodiversity is the idea that people interact with and experience the world in a multitude of ways and, as such, there is no "right" way of thinking. Therefore, differences are not viewed as deficits but rather as a human specificity that should be respected (Ortega, 2009). In theory the Neurodiversity movement is supposed to be a multifaceted undertaking that celebrates the unique combination of an individual's abilities, perspectives and needs. However, given that the roots of this movement lie in the Global North, when one looks deeper, it is reduced into a binary of "typical" versus "atypical" (Nair et al., 2024). The movement has often overlooked pre-established knowledge systems (such as indigenous and cultural beliefs) that celebrated neurodiversity before it was brought into "mainstream" research (Russell, 2020). It is hardly groundbreaking, the assumption that human beings as individuals are unique and furthermore that we should be able to be accepting of this individuality. The umbrella of neurodiversity is walking a tightrope of ableism when all we see is the rain and we fail to see the uniqueness of each rain drop. Though there is plenty to critique within the movement, for the purpose of this study, neurodiversity will be the overarching term used to describe each child and family that participated in the research as their given diagnoses (Autism and Downs Syndrome) are classified under the term Neurodiversity at present.

Ableism is pervasive (Dethorne & Gerlach-Houck, 2022; Nair et al., 2023; O'Connor & Pettigrew, 2016). It is a network of processes, practices and beliefs that idealise typical bodies, typical values and typical ways of thinking (Bogart & Dunn, 2019; Donaldson et al., 2023). It breeds discrimination, stigma and inequality and sees individuals with disabilities as "less than" (Bogart & Dunn, 2019; Chouinard, 2014; O'Connor & Pettigrew, 2016; St. Pierre & St. Pierre, 2018). "Able-bodiedness" was constructed by a white eurocentric standard of physical ability (Nair et al., 2023). Colonialism heavily influenced this construct by creating a hierarchy defined by categories such as gender, race and disability (Nair et al., 2023).

This means that able-bodied white men were the standard, while disabled black women were consistently at the bottom of this human pyramid as they were oppressed from a gender, race and disability perspective. This rhetoric continues to ripple through our world and the profession as well (St. Pierre & St. Pierre, 2018). In recent years, the neurodiversity-affirming movement has been colonised as well and reduced to a binary comparison as an opposition to neurotypicality (Singh, 2023). Focus should instead be on the acceptance of different neurocognitive styles rather than the comparison between neurotypicality and neurodivergence (Singh, 2023).

Ableism is no stranger to the profession either (Donaldson et al., 2023; Nair et al., 2023). In traditional SLT practices, all assessments are measured against norms, all children are judged against a set standard, and the entire profession is created on the notion of spotting the difference (Nair et al., 2023; Sisskin, 2022; Wetherby et al., 2018). Difference is the business, but the business is not in the habit of celebrating those differences, rather the entire premise is on how to fix them (Dethorne & Gerlach-Houck, 2022; Sellwood et al., 2022). SLP is no exception. Traditional SLP practice has been shown to have limitations when it comes to serving people with disabilities. Many interventions have been focused on a viewpoint of communication that is ableist and heavily influenced by colonialism and therefore aims to "normalise" the disability as opposed to using an individual's strengths to support and empower them (King et al., 2014).

One of the most recent campaigns of disability advocacy groups is "Nothing about us, without us", which is ironic considering that individuals with disabilities are the most underrepresented in the social justice space (Hughes, 2016). Individuals with disabilities are frequently excluded from significant conversations that impact their lives. When it comes to "mainstream" media discourse, activism and high-level policy discussions, disabled voices are often silenced if not entirely erased (Chapman & Carel, 2022; Hughes, 2016). Neurodiversity in particular is most commonly framed by neurotypical perspectives which perpetuates stereotypes and stigma and reaffirms ableist views (Shields & Beversdorf, 2021; Singh, 2023).There is a need for the neurodiversity movement to link more closely with disability justice movements to ensure that intersectional perspectives are accounted for.

Oftentimes, the neurodiversity movement glosses over the individualism of the people who fall under the umbrella. For example, experiencing disability as a white man and a gender non conforming person of colour are two very different experiences. Similarly, many disability justice movements don't explore the impact of oppression – particularly economically, socially and racially. The neurodiversity movement and disability justice movements can do more to center and amplify underrepresented perspectives.

Within the field of Speech Therapy, there are whispers of the neurodiversity movement in certain pockets of the profession. There is more recognition of all forms of communication being valid and less emphasis on "fixing" when it comes to Autism. There is a call for a shift away from teaching children how to make eye contact and deeper exploration of the double empathy problem (i.e. when people with very different experiences of the world interact with one another, they will struggle to empathise with each other). There is the use of identity first language and a focus on strengths based models of intervention. But while there are these practical changes, the core of the work hasn't changed. The assessments are not developed to find strengths and the intervention is still child focused. We are still Pathologists. There is much more work to be done for the neurodiversity movement to truly embed itself in current practice.

3.6. The Need for Community Practice

3.6.1. The Might of Community

As an adult and a speech language pathologist (SLP) working with children with a variety of communication backgrounds, it is vital to get to know the most important people in the children's lives in their home language. So, whether it is a "*Vovo*" or "*Oupa*" or "*Umkhulu*", it is always important to know because therapy starts with community. SLPs need to be asking more questions around family, friends, hobbies, favourite foods, important places, key people — questions that help us understand who the children are, because we cannot even begin to provide the support that is needed until we know that. We need the stories, the bigger picture. As South Africans, we are inextricably bound by the concept of *ubuntu* (humanness). It is a philosophy that encompasses self-identity, lived experience, and a bond of sharing that connects humankind (Nabudere, 2005). It is idealistic in its pure form, and flawed in reality, but there is a skeleton of hope that it represents that can be nourished and brought to life by community.

Simply put, it means “I am because we are.” (Khoza-Shangase & Mophosho, 2021; Ngondo & Klyueva, 2022; Ogude, 2019; Peterson, 2019). I believe, *ubuntu* has a key application in the field of speech language pathology where communication is a link as powerful and binding as this philosophy. Communication should be community, inclusion and belonging. Embracing *ubuntu* as SLP practice means that we can focus holistically on the person and their community rather than just focusing on the clinical. These roots of humanness should be grounding the work; we should not be afraid to centre the person instead of their diagnosis.

As humans, we are uniquely gifted to be able to communicate in a multitude of modalities, all of which hold power (Donaldson et al., 2017). And yet not all are regarded as holding the same power. There is an immediate sense of fear that accompanies parents who are faced with going down the path of accessing alternative communication (Berenguer et al., 2022; Donaldson et al., 2023; Hourcade et al., 2004; Mandak & Light, 2018). There is pressure too, for a speech therapist who is not focusing on speech (Solarsh & Johnson, 2017). This alternative way of communicating is alien for families and it will continue to be so if SLPs don’t evolve into therapists that open up communication to a wider world (Miolo & DeVore, 2016; Staley et al., 2022).

Author reflection: One of the most profound underpinnings of inclusion is communication. When I think of community, I think of all the moments in my life where I belonged. These varied from my favourite cozy Saturday night dinners with the family, to sitting in the sand on a Durban beach watching the 2010 FIFA Soccer World Cup Final, surrounded by strangers but part of something much bigger than myself. Our communication on those nights felt like collective osmosis — where words were not needed to transcend the barrier of understanding. Whether it was the subtle scraping back of a chair as the first person rises to break the spell of a meal; or the roar of a crowd so deafening I’m surprised it didn’t awaken a kraken offshore. Communication felt effortless, unified, and interconnected; it was a collective inhale and exhale. What if we as SLPs tried to create moments like these for every child in our caseload? What if instead of focusing on deficits, we focus on cultivating interests and strengths in its place? What if we focused on weaving connection and harnessing the might of community? I believe we can. I believe we should.

It warrants the question, why are we limiting our communication support when we place the burden of communication on the child and the family and caregivers? Surely, anyone that offers assistance to the public should be adequately equipped to understand AAC so that we can create moments of inclusion. We are using alternative communication in almost everything we do from responding to texts with emojis to online shopping. I remember the power in being able to able to order my first Big Mac, it was a heady thing and in my adult life, both a blessing and a curse. Now you can do it all on a screen without saying a word.

Speech has long been the gold standard for communication but for a world increasingly dependent on technology, speech is becoming a secondary method of communication for an entire generation (Lee & Cherney, 2022). The reality of AAC becoming "normal" and "acceptable" is much more nuanced than it is made to sound here, but it is a possibility. It comes with sharing the load and harnessing the power of community. The most current evidence for best practice in our field explores ways to restructure clinical practice so that it can reach multicultural clients. Along the way, that exploration has led to the glaring fact that traditional practice does not gratify this need (Brouse, 2023; Staley et al., 2022).

3.6.2 Why Community is Key

A community focus, brings back the humanisation of communication, connection and belonging; a place where we can be ourselves effortlessly and unapologetically. This is what everyone wants and deserves. It is true that most children learn how to communicate through interactions with others, so families need to be centred in practice as the foundation of this learning (Burke et al., 2018; Henner & Robinson, 2023; Mandak & Light, 2018; Roman & Sonn, 2017). When it comes to raising a child with a disability, intervention needs to take into account the nuance of each family and the individual needs of their child in order to meet them effectively (Lee & Cherney, 2022; Robinson & Notara, 2015). In doing so, families become meaningful partners, active participants and key stakeholders in the development of communication plans and programs (Klatte et al., 2020). The magic of treatment happens in the reciprocity of the relationship between the SLP, family and child. That is not to say that the magic happens easily, sometimes the partnership is hard fought and you dig deep to find it. This is true for many South Africans with a communication disability (Harsha Kathard & Pillay, 2013; Pillay & Kathard, 2018).

In saying this, it is worth noting that part of community engaging means taking off the expert hat and accepting that learning is a two-way street. As much as communities can gain from SLPs there is also much SLPs can gain from community. It has become increasingly more common in developing countries to explore community-based practice (Prathanee et al., 2010; Wickenden, 2013). This way of practicing has been useful in providing service where there is a lack of SLTs or barriers to access or limited resources — challenges that the profession faces in most of the Majority World (Abrahams et al., 2022; Staley et al., 2021; Wylie et al., 2016). The call has been made by therapists in these contexts for a shift away from traditional practice (James Law et al., 2013; Marshall et al., 2017; Pillay et al., 2020; Wylie et al., 2016).

The concept of community is a multi-layered and complex one that consists of interconnected relationships, shared culture and geographical location (M. Anderson et al., 2003). By building relationships with communities, SLPs can gain valuable insight into the context of a family, their cultural influences and their participation in society (Verdon et al., 2016). It is a rich context in which SLPs can learn through and use to gain a better understanding of dynamic global environments and their professional role in them (Law et al., 2013).

3.6.3. Inclusion and Belonging

For many years, people with disabilities have been marginalised by physical and societal barriers that limited access to and participation in their environments (Darling, 2013a). The concepts of connectedness and belonging are crucial to understanding social inclusion. They are multifaceted, dynamic ideas that are constantly changing and evolving (Robinson et al., 2020). It is a long-term process to gain a sense of belonging and requires deep emotional investment. Though desired by so many, it is often challenging to achieve (Lazarus et al., 2016).

Research from the Global North has shown that nuclear families that have strong support networks, both formal and informal, have the resilience to better support and manage their children with disabilities and advocate for inclusive spaces (Robinson & Notara, 2015). How families are viewed and treated at the time of diagnosis can have long-lasting effects on their ability to manage expectations of their lives going forward, and their sense of confidence and control of getting through the day to day (Manono et al., 2021; Roman & Sonn, 2017). Having peers, friends and family they can trust as sources of information and referrals also plays an important role in the overall connectedness of a family to their community (Milner & Kelly, 2009).

Ultimately, it is often the family and the disabled individual that bear the burden of the responsibility for inclusion as they are required to change in order to "fit in" with society (Robinson et al., 2020) — whether it is the mother who is raising a child alone, or a grandparent who is a long-term caregiver. Research of the Global North with a medical model focus frequently creates generalised norms which in turn creates the "problem" of the disabled child, focusing on the deficit discourse of disability (Curran & Runswick-Cole, 2014).

Within the profession, the terminology SLPs use has implications on how the profession views disability, starting with the "pathology" aspect of the degree itself (De Bortoli et al., 2014). One of the overarching components of belonging and inclusion is communication, which plays an important role in many lives of children with disabilities (Solarsh & Johnson, 2017).

3.6.4. The Spirit of Ubuntu

There are international organisations that have tried to lend their input into inclusion and belonging by introducing policies like The United Nations Convention on the Rights of Persons with Disabilities which protect and ensure the rights and freedoms of disabled individuals (Slater et al., 2020). It was, however, only adopted by 174 countries around the world, was still located in the imagination of the Global North, and left many people with disabilities still facing barriers within their communities from the attitudes of the general public to the stigma around and discrimination against those with disabilities in many cultures (Scior, 2011). These policies almost always refer to the individual experience of disability, while Africa has a greater focus on community and communal living. An aspect that might have the potential to be a better response to disability (Finkelstein, 2001; Roman & Sonn, 2017; Staley et al., 2021).

Ubuntu lends itself to the idea of a universal family — one where the load is shared, the burden is carried together, and the joy is celebrated collectively (Berghs, 2017b; Precious, 2017; Tusasiirwe, 2022). *Ubuntu* is more than just a philosophy, it is a moral education that has spanned generations (Etieyibo, 2017). The virtues instilled through the concept of *ubuntu* create a sense of humanity that Western teachings of morality do not provide. Instead of teaching principles, it teaches critical and reflective thinking (Etieyibo, 2017). However, like most philosophies, it has had its struggles finding its place in a modern world (Louw, 2019).

Sometimes it creates a paradox between the warmth and hospitality of the philosophy itself and the struggle for equality and basic human rights that many still experience (Boessenkool, 2006). It is the understanding that humanity is created through our relationship with other humans. It is South Africa showing up for Palestinians half a world away. It is courage and compassion. It does not watch from the side-lines or shy away from sharing a burden (Khoza-Shangase & Mophosho, 2021; Ngubane-Mokiwa, 2018). In its pure form, in an unburdened world, *ubuntu* gives strength to voices who challenge the West.

3.6.5. Why Ubuntu Matters

Ubuntu is an African Philosophy that proposes human existence as a communal experience (Berghs, 2017a; Khoza-Shangase & Mophosho, 2021; Ndlovu & Nyoni, 2021; Ngubane-Mokiwa, 2018). Knowledge is gained through others and the human experience is central to it all — it is a unique combination of recognising individual identity but having that identity belong to something bigger (Chisale, 2020; Etieyibo, 2017). It is common in disability research that people with disabilities are something to be studied, participants, but rarely co-creators of knowledge even though they hold the key to unlocking it (Ned, 2022).

For SLPs, the focus of transformation should be on the Africanisation of the profession and its training — recentering Africa within a framework of decolonisation — and in innovating what comes next rather than just keeping up with best practice (Khoza-Shangase & Mophosho, 2021). For a profession that is a product of the Western World, this is not easy to do. After all, African societies moulded by colonisation do not serve African communities but Western ones instead (Cluley et al., 2023). For starters, we can look at providing SLP training in a variety of languages, we can work on developing more resources that are based on African experiences and can look at co-creating therapy in a way that works for each individual and those around them (Cluley et al., 2023; Harsha Kathard & Pillay, 2013; Staley et al., 2022).

This emphasis on diversity, cultural sensitivity (the undoing of a Western Norm) and human rights, means that SLPs need to engage with the communities they serve in order to facilitate necessary change (Milner & Kelly, 2009). Practitioners need to actively engage with communities and acknowledge the input of disabled individuals themselves, in order to offer a safe and culturally sensitive approach to engage families who might otherwise not access these services (Verdon et al., 2016).

In 2023, data from the World Health Organisation estimated that around 16% of the world's population is disabled, with more than 80% concentrated in the Global South (Goldiner, 2022; World Health Organization, 2023). Despite disability studies having gained some attention in recent years, this is almost always through the lens of the Global North with a focus on the voices of northern academics and activists (Grech, 2015). This means that the Global South is effectively excluded from the narrative of eurocentric disability studies (Grech, 2015; Pillay et al., 2015).

Therefore, the study of disability rights requires emancipation from the cultural, economic and political domination of colonialism (Abrahams et al., 2022; Chouinard, 2014; Meekosha, 2011). This is particularly true for a population as complex and diverse as South Africa. When Nelson Mandela left Robben Island after 27 years in prison, he used *ubuntu* to heal a fractured nation. Through his humanness and compassion and faith in community (and that indomitable South African love for rugby) he led us out of the darkness. We have experienced first-hand, the power that community holds when wielded. *Ubuntu* is a force, an unmatched power, a shelter, and a way forward we should take heed to follow.

The profession has promise and potential to grow, to serve and to branch out in numerous ways in order to make a difference to the furthest reaches of the world. But we need to be bold and brave in order to get there. We need to keep asking the difficult questions.

3.7. Decolonising Research: A new way of Doing, Being, Creating and Practising

Decolonisation is a concept that has taken roots in communities across the Majority World (Abrahams et al., 2019; Harsha Kathard & Pillay, 2013; King et al., 2014; Mashau, 2018; Tusasiirwe, 2022). It is a movement that aims to decentre Western and Eurocentric focused research and give power to Afrocentric methodologies and indigenous knowledge (Chigevenga, 2022; Grech, 2015; Meekosha, 2011). However, there are a number of barriers that exist when it comes to advancing this research. Power imbalances and past social injustices, as well as African research conducted by non-Africans, skew the lens of what it means for research to be decolonised (Chigevenga, 2022). To decolonise this, we would need critical reflections on our current approaches and to focus our energy on the small changes we can make that will positively impact the children we see (Keikelame & Swartz, 2019). We have to challenge the relevance of our current Eurocentric worldview within the profession. In South Africa, speech therapy services are gatekept by privatisation, political warfare and socioeconomic inequality to name a few (Kathard & Pillay, 2013; Pillay & Kathard, 2018).

Author Reflection: The South Africa I know is my neighbours unbounded pawpaw tree, the fruit that quenched our thirst over the summer and the giant pots of food shared across a laden table. The South Africa I know, and more importantly the community I was born into, is not selfish, it does not put up boundaries and it certainly should not. The way of working that we have become accustomed to doesn't share the wealth at the table or the fruit of our neighbours labours. It is a tight and disciplined practice that happens behind closed doors to those who are deemed worthy of receiving the help or who are able to afford it (Abrahams et al., 2019; Khoza-Shangase et al., 2021)

There is great capacity within the profession to push outwardly, to fling open the windows and knock down the walls from the inside — to make the change happen instead of waiting for it to come (Abrahams et al., 2022; Hyter, 2014; James Law et al., 2013; Verdon et al., 2015). The foundation of the profession, as well as its recent history, unfortunately rests in the hands of the Global North with a medical model focus (Abrahams et al., 2019; Donaldson et al., 2017). It frequently creates generalised norms and standards for practice to abide by which in turn creates the "problem" of the disabled child, the communication impairment, the language disorder, or the speech difficulty. Or focusing on the deficit discourse of disability and individuals who do not follow the norms — problem, problem, problem, problem (Chouinard, 2014; Curran & Runswick-Cole, 2014; Roman & Sonn, 2017). The profession and the way it sets up the clinician/client relationship within the medical framework is cold and detached when the essence of communication is connectedness (Anderson et al., 2015; Mandak & Light, 2018).

It is often case histories that dissect a life. Carefully crafted questions designed to get to the root of the problem, followed by an uncompromising assessment, and tied up in a bow with session plans and rationales; the whittling down of a life into a few pieces of paper (Donaldson et al., 2017; Nair et al., 2023). This emphasis on diversity, cultural sensitivity (the undoing of a Western norm) and the access to and acknowledge of human rights, means that SLPs need to engage with the communities they serve in order to facilitate necessary change (Milner & Kelly, 2009).

The decolonising researcher needs to display a critical understanding of the assumptions, values and motivations that inform and underpin research practices in order deconstruct and reconstruct knowledge (Chigevenga, 2022; Keikelame & Swartz, 2019). Research then needs to be centred around the world views of individuals from the Majority World, shifting the lens and respectfully engaging with alternative knowledge to transform colonised perspectives (Grech, 2015; King et al., 2014). In doing so, research becomes a collaborative space where past and present learnings can be used to transform methodology (Sinclair, 2003).

3.7.1 The Stories We Tell

For many years, the positivist paradigm has been the lens through which most science and research has focused (Botma et al., 2010). It falls under the traditional umbrella of hypothesis testing and observable facts, where the researcher is not a part of the reality (Asghar, 2013). This is a notion that is difficult to separate when human beings themselves are subject to specific biases and viewpoints based on their own lived experiences (Zuber-Skerritt, 2001). While this research has shown promise in allowing researchers to understand the laws of science in quantitative contexts, it does not allow the researchers' own values to be present in the study — a shortfall which severely impacts the outcomes of qualitative studies in particular (Botma et al., 2010).

Storytelling has long been a source of knowledge sharing with methodological grit in many African cultures (Susana Caxaj, 2015; Tusasiirwe, 2022). It is a ritual of coming together, teaching, learning, and keeping history alive (Tuwe, 2016). Traditional stories have been crafted from human experience and shared in narratives, songs, poems, and dances — the stories are almost always centred around humanity and shared amongst community (Sium & Ritskes, 2013; Tuwe, 2016). Colonisation has stolen the power of storytelling from the African culture and reduced the significance of it as a methodology (Dohan et al., 2016; Holley & Colyar, 2009; Sium & Ritskes, 2013; Stansfield, 2020).

The westernised ideal of research is numbers, percentages, and statistics (Clandinin, 2006; Thambinathan & Kinsella, 2021). Theory has reduced the human experience to graphs and tables which makes little sense when communication is such an individualised human experience (Lindsay & Schwind, 2016; Sium & Ritskes, 2013). Stories have the ability to give power to those telling them and, in doing so, guide our practice and goal setting more than any assessment on paper can. In addition to this, stories highlight the nuance of communication, community, and the lived experiences of inclusion and belonging that people with communication impairment experience.

3.8 Repositioning Practice

The profession of SLP has largely been shaped by colonial influence with the SLP positioned as the expert service provider (Pillay et al., 2015). The western medical model of training was, and still is, too simplistic for the complexity of the South African population with diverse cultures and backgrounds (Pillay et al., 2015; Weddington et al., 2003). Its strong colonial roots mean that SLP graduates are not trained to adequately address the needs of these individuals and lack the linguistic diversity, cultural sensitivity, and overall understanding of differing belief systems within the country and within communities (Khoza-Shangase & Mophosho, 2018).

In the past, power has been given to certain kinds of knowledge; that which is evidence based and measurable and reductive (Butler, 2019; Jull et al., 2017; McCurtin & Roddam, 2012). Practices that challenge this knowledge base are often considered less valuable or legitimate and can be excluded from practice despite their value (Justice, 2010). One of the cornerstones of our professional practice is the clinical reasoning that allows us to integrate our knowledge and experience to arrive at an intervention plan (Johnson, 2006).

Ultimately our experience is based on empirical theory and knowledge but it would be difficult to explain away the variances in our practice based on personal beliefs and professional experiences/judgements (Justice, 2010). Textbooks full of facts and certainties are a common part of speech therapy education. But when a child is sitting in front of you, it is not the textbook that ultimately decides what intervention would be best. Best practice definitely exists, but it is one small part of the decision-making process. It is not new to the profession that two therapists can recommend two different interventions for the same child. This indicates that our personal experiences are key to our practice and yet so much of our profession tries to remove the personal thread.

South Africa is just one of many Majority World Contexts within which the profession of Speech Therapy is struggling to adjust (Staley et al., 2022). There are many challenges the profession faces in environments that struggle to assimilate to its Eurocentric roots. There is a craft to creating interventions that honour the families, the children, and their communication needs. But in order do that, we need to consider transformation that looks at country specific practice, practitioner experience, and the intersectionality of families.

In the last few years, many students in various fields across South Africa have experienced frustration with the lack of transformation within the SLP curriculum (Morreira, 2017). Gaps were identified in the SLP programme with regards to knowledge, teaching and practice that prevented new graduates from being holistically prepared to provide services to South Africa's diverse population (Kathard et al., 2007; Moonsamy et al., 2017; Pillay et al., 2015; Watermeyer & Barratt, 2013). Although the profession has been undergoing transformation for the last 20 years, the reform of academics, curriculum and policy has been a slow journey (Moonsamy et al., 2017). Most higher institutions of learning in Africa are still heavily invested in western ways of creating and sharing knowledge (Tusasiirwe, 2022).

For SLPs, the focus of transformation should be on Africanisation of the profession - recentering Africa within a framework of decolonisation - and its training and in not just keeping up with best practice, but innovating what comes next (Khoza-Shangase & Mophosho, 2021). SLPs require a more informed view on communication as a whole, as well as communication "disabilities and disorders" that challenge explanations normalised by the Global North but includes explanations relevant to the Global South (Wylie et al., 2013).

In addition to this, SLPs need a deeper understanding of the contextual factors that influence disability in a world with an increasingly diverse national, cultural and linguistic population (Abrahams et al., 2019; Harsha Kathard et al., 2011).

Change is difficult for the profession. Even now, so much of the practice has remained the same since it reached South African shores (Abrahams et al., 2019; Pillay & Kathard, 2018; Staley et al., 2022). And yet, while so much around the profession has changed, there is more of a need for SLT services. Even with linguistic diversity, multicultural variety and much inequality, little has changed in terms of practice (Duchan, 2023; Khoza-Shangase et al., 2021; Moonsamy et al., 2017; Pillay et al., 2020; Seabi et al., 2014).

Studies conducted in psychology and social sciences found that change is often dependant on cultural values, sociodemographic conditions and learning environments (Chen, 2015; de la Sablonnière, 2017). Systemically, South Africa has a long way to go in order to mitigate factors including socioeconomics, geographic and race that have been impacted deeply by apartheid (H.C., 2014; Irlam, 2004; Moonsamy et al., 2017). However, within the profession, there is opportunity for change that can be fuelled by a diverse range of cultural values and shifts in learning environments (Chen, 2015; Morreira, 2017; Wylie et al., 2013).

Current practice could benefit from a radical shift away from traditional clinic-based practice. This is to ensure that individuals receive comprehensive and integrated services that contribute to inclusion within various contexts, and participate actively in the process and determine their own outcomes (Schneidert et al., 2003; Swain, 2011). In this regard, community experiences can be instrumental in transforming practice as listening to stories of community members can provide a new learning context for SLPs in many environments. Therefore, the focus of this study will be on learning through narratives of families who have children with disabilities; documenting their perspectives and experiences with acceptance, inclusion and belonging in their communities. These stories can be powerful vehicles for change when harnessed effectively in order to inform and evolve SLP practice through community engagement.

This study asks the question: How can SLPs evolve their practices through learning from community narratives of acceptance, belonging and inclusion of children with complex communication needs?

Chapter 4 - Methodology and Design

This chapter explains the research question, study aims and objectives, and overall methodology. While the process of generating data seemed quite straightforward and simple in its imagining, this study's analysis had layers of complexity that will be outlined below.

4.1 Aims and Objectives

Aim 1: To explore family narratives of acceptance, belonging and inclusion within families and community spaces.

Objective 1: To listen to the dreams, hopes, visions, long-term goals and perceived barriers that caregivers of children with complex communication needs experience within their communities.

Objective 2: To understand community perspectives of how to create inclusive environments for children with special needs.

Aim 2: To explore how stories of community engagement can evolve future practice for SLPs in community spaces when working with a special needs population.

Objective 3: To identify key learnings from stories of acceptance, belonging and inclusion.

Aim 3: To propose a practice framework to reposition future community-informed SLP practices

4.2. Research Design

For the purposes of this study, a narrative research design was used throughout the study. Narrative research design is the study of how individuals experience the world (Moen, 2006). Storytelling is a powerful tool that can be used in creating social change and shifting pedagogical focus in the health science field (Chen, 2008). Using narratives to get access and insight into people's experiences has gained a lot of traction in the past few years, initially within the social sciences but now within the medical profession as well (McCance et al., 2001). In my work as a paediatric SLP engaging with families and neurodivergent children, I found that stories have the power to transform and influence practice and purpose which is why narratives were so highly valued as a methodology. The experiences of individuals play a key role in informing practice (Lindsay & Schwind, 2016; Smith, 1999). Most people communicate through storytelling and narratives, which is why it is vital that these stories were included in this research (Dohan et al., 2016).

Narrative methodology allows researchers to get to the core of an experience (Chen, 2008; Coulter et al., 2007; Tusasiirwe, 2022). It is an effective research method for learning about social experiences and deepens understandings of complex issues in ways that rigid, positivist approaches to research cannot (Miller & Bridger, 2019) The application of the narrative design is easily identified in Aims 1 and 2 as well as their related objectives. However for Aim 3, it was equally as important but perhaps less clear. The narratives form the basis of the practice framework as the catalyst to learning.

Without the narrative design, the practice framework would default to the medical model roots and traditional learning that this study is trying to move away from. Narratives were also used throughout Chapters 1 and 2 for my own reflections and interpretations further highlighting the overall narrative design of the study, and the pervasiveness of stories, as a way to make meaning of an experience.

When considering decolonialising research, narratives are an emancipatory tool that can be used to explore and validate the experiences of those who have previously been oppressed (Marsters & Sim, 2019; Sium & Ritskes, 2013; Susana Caxaj, 2015). It can also be used to support more traditional evidence that is used to ground quantitative research (Marsters & Sim, 2019). Furthermore, it allows professionals and the individuals they serve to reflect on shared values and beliefs, and explore assumptions that have the power to guide practice, connect patient and health care provider, and inform professional agency (Marsters & Sim, 2019).

Stories are crucial in repositioning practice as they bring lived experiences to the fore and share insight around concepts like inclusion and belonging that are difficult, if not impossible, to quantify through quantitative research methods. Narratives have the ability to shift power dynamics and to include the research participants in making meaning of the study rather than just act as passive points of data collection. In this study, stories were used in two ways: Firstly, to generate understandings of family and community experiences of acceptance, belonging and inclusion; and secondly as pedagogy tools where stories were used as a basis for engaging in thinking about repositioning SLT practices (Coulter et al., 2007; Landrum et al., 2019). The principles of pedagogy highlighted in this study will be around mutual learning.

Figure 1

Illustrating the layers of Narratives in the Research Design

4.3. Study Protocol Phases

This sequential qualitative study was conducted in four phases:

(1) Pilot Phase

(2) Phase 1 addressed Objective 1: Generating Family Narratives

(3) Phase 2 addressed Objectives 2 and 3: Generating Community Narratives

(4) Phase 3 addressed Objective 4: Generating a practice framework

Figure 2

Flowchart highlighting the study protocol process

The study design will be presented in the order of each phase.

4.4. Pilot Phase

The pilot phase was used to trial and assess the data collection and analysis of Phases 1 through 3 (Lancaster et al., 2004; Thabane et al., 2010). I used it to practice data collection strategies and adapt them where necessary as well as to gain experience in analysing the data collected. The pilot data was rich and thought provoking and therefore included in generating the findings of the study.

4.4.1 Pilot Family and Community Interview Reflections

I used the pilot study to familiarise myself with the research process when conducting a narrative interview. For the interview stage, I chose a family known to me to decrease the pressure of carrying out such an intimate interview for the first time. The role of clinician vs researcher was clearly explained before conducting the interview which was a key step in setting the tone for the relationship. This interview taught me important skills like knowing how to hold back, how to create space for sharing, and how to ask meaningful open-ended questions to get the insight of families. Knowing the family allowed me to ask meaningful follow up questions, having some contextual background of their story and knowledge of their journey. There is an automatic power dynamic that occurs between a researcher and a participant and it was helpful to learn how to manage this in the pilot.

The recording of the pilot interview was vital as it was a cornerstone of my learning. Listening to the interview, I was able to more clearly pinpoint where I needed to hold space instead of filling it and I was also able to hear when my questions were leading vs open ended and how that changed the answers from this family. While there was a schedule of interview questions, the prior knowledge I had of the families' experiences intersected with the aims of the project, which allowed me to give some thought as to when the interview questions were asked for the best flow and to maintain the integrity of a narrative as well as minimally disrupt their stories.

In order to remove some of that expectation of the participant needing to "give data" to work with, additional time was taken at the beginning of the interview to set the scene about the "why" behind the project and how it was their stories and personal experiences that I was listening to — whatever that may have looked like. Going forward, I chose families that I knew due to the nature of the interview.

Narrative interviews were chosen to support this narrative methodology as they really "humanised" the research and highlighted the core of the families stories (De Fina & Georgakopoulou, 2015; Hughes, 2016). Using this form of interview also allowed me to co-create the knowledge with the family and moved away from more static interview approaches (Keikelame & Swartz, 2019; McCormack, 2004). Though it does raise issues around subjectivity versus objectivity, ultimately, this research and these interviews were very personal to each family which was the desired outcome – the humanity (Gubrium & Holstein, 2012; Siedman, 2006). Bias of families and the researcher was closely monitored and acknowledged throughout.

The pilot community interview was my first foray into conducting an interview with an unfamiliar person with this lens. It was an important experience in learning how to establish rapport and then use that as a foundation to build on. I went to an establishment that was familiar to the participant to conduct the interview which helped set the tone of the interview and decreased some of the anxiety — this was something I remembered to carry over into the main study, to offer a variety of venues to the participant for comfort and autonomy.

The pilot analysis phase was a challenging experience. It seemed daunting to take the words of the interview and transform them into something worthy of being called an analysis. The data were plentiful and the stories were heavy with the weight of their significance. At first, the thought was to analyse each story in a different way with a style suited to each family but it was methodologically complex and more difficult to develop an understanding of key themes that arose for each family. While each story was entirely different, there were similar themes that emerged. The family and community interviews were initially separate but it became evident that the family influenced the community and the community influenced the family and such relationships could not be parted. Therefore the family and community narratives were merged.

4.5. Phase 1 Generating Family Narratives

4.5.1. The power of narratives

Historically, the dominant narratives of parents raising a child with a disability have been heavily focused on the hardship and tragedy of neurodiversity that the deficit based medical model still interprets as being burdensome on a family (Lalvani & Polvere, 2013). The presumption of pathology within this limited model means that the child's impairment is often interpreted as the cause of distress and exclusion without any consideration for the societal, cultural or environmental impacts on the family as a whole (Collier et al., 2015).

It was therefore vital to situate families' experiences, stories and reflections as central to research aims that intend to deconstruct knowledge about what disability means to a family and a community (Lalvani & Polvere, 2013). Narrative interviews allow me to place the interviewees at the heart of a research study. Instead of focusing on the actual words being said during an interview, the narrative analysis approach creates room to collect data on how the interviewees expressed themselves, the language they used when describing an event, and the thoughts and feelings they experienced (Susana Caxaj, 2015; Thomas et al., 2021).

4.6. Phase 1 Participants

4.6.1. Inclusion criteria

Families who have a neurodivergent or physically impaired child between the age of 0 – 10 years were included. Primary caregivers, family members, non-parental caregivers (e.g. grandparents, aunts, uncles), and siblings in the family were also included in these criteria if they played a role in interacting with and caring for the child (e.g., being responsible for watching over them, fetching them from school, babysitting etc.). Here, family was determined by each participant. It was also beneficial to interview families who have accessed SLP or other allied health services so that they were able to comment on their experiences.

4.6.2. Exclusion criteria

Families who were not able to commit to the time frame of data collection in order to support prolonged engagement practices were excluded from the study. Families already involved in other research projects were excluded in order to reduce the burden on this population.

4.6.3. Sampling

The sampling frame here included families that represented the diversity in South Africa in terms of race, socioeconomic status and location (rural and urban). While the sample size was small in order to focus on the unique backgrounds and experiences of each family, the goal was to ensure that not just one race group or socio-economic class was focused on. It was an important consideration because within the post-apartheid South African context, race, economy and location all play a pivotal role in experiences when it comes to disabilities (Botha & Watermeyer, 2021). Purposive sampling was used in order to ensure that the participants selected would be most beneficial to the aims and objectives of the study (Etikan et al., 2016). Participants were interviewed until data saturation was reached (Guest et al., 2006). Data saturation was important to establish an adequate sample size for qualitative research and data collection (Guest et al., 2020).

4.6.4. Recruitment

Participants were largely recruited using word of mouth. Additionally, participants were recruited via social media using: email, informational flyers shared via social media (Instagram, WhatsApp, Facebook etc.).I approached families I knew in a professional capacity to participate as long as they met the sampling criteria. In these cases, it was vital that I acknowledged the impact of the "self" on research in order to account for the prior therapeutic relationships that might have existed (Hobson, 2004). Where I had a longstanding clinical relationship with the family, I exercised care in explaining my researcher role.

4.7. Phase 1 Data Collection Method

4.7.1. Narrative Interviews

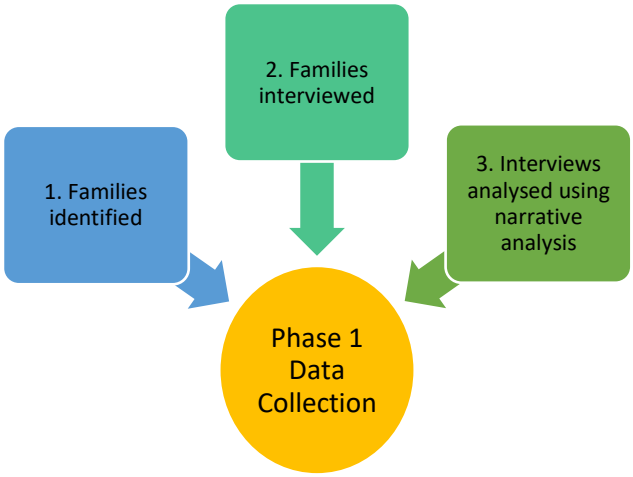
In this phase, four families who have children with disabilities were interviewed to gain their insight and perspectives on living with and caring for a child with different needs with an extended focus on community engagement and inclusion. Narrative interviews were used to discuss the areas highlighted in the aims and objectives above. A narrative interview provided the chance for the families to narrate their experiences in their own words instead of placing emphasis on the typical question-answer format (Scârneci-Domnişoru, 2013).

It allowed a shift into narrator–listener rather than interviewer–interviewee which provided a rich source of data (McCormack, 2004). By using open-ended questions, the researcher created a space for participants to tell stories in their own words and co-create the story within the interview (Lindsay & Schwind, 2016).

Initially, one-on-one individual narratives were used to create a collaborative storytelling experience which allowed families to share perspectives and emotions (Kiser et al., 2010). Narratives were an ideal tool to use in order to help SLPs transform community practice (Lindsay & Schwind, 2016). The interviews were used to explore the families' experiences from the time of the birth of their child with special needs to the day of the interview (Thunberg, 2021). There was flexibility here for who the storytellers were within families which was determined by the family themselves. While the option for a one-on-one interview was given, families were also given the option of being interviewed together.

Figure 3

Summary of Data Collection Phase 1



4.8. Phase 2 Generating Community Narratives

4.8.1. Using stories to enhance community practice

When thinking about community engagement development, one of the best approaches to learn what people are thinking, what they need and what they value, is by listening to their stories (Solinger et al., 2008). Across the world, the focus on public health has been on reducing health inequities through exploring what participation, well-being, belonging and advocacy means for diverse audiences (Marsters & Sim, 2019).

Therefore, community engagement through narrative has been lauded as a valuable and effective strategy for improving patients' health by engaging in meaningful conversations (Brunton et al., 2017). Even a single narrative can change the way professionals practice in their field or reform policies around public health by creating reciprocity within the learning experience (Chen, 2008).

Stories help in developing professional empathy and investigating ethical issues in professional practice (Solinger et al., 2008). By linking professional practice and collective personal narratives around identity and experience, researchers are able to understand service provision more holistically (Clandinin & Caine, 2013). This has also been explored in fields such as disability studies and social work — areas of study that explore the human experience in order to better the lives of others (Grech, 2011; Hernández-Saca et al., 2018; Hiranandani, 2019). As such, community-focused research has become the leading paradigm with which to develop approaches and strategies that improve intervention and service provision in diverse communities (Thomas et al., 2021).

4.9. Phase 2 Participants

4.9.1. Inclusion criteria

The following groups of people were included in the study:

- Community members (religious leaders, family members, service providers — e.g. individuals who run extramural activities, shop assistants, waitrons, government workers etc.) who have been identified as creating inclusive environments for families;
- those who have children with disabilities;
- or community members who have been identified as creating barriers toward inclusive environments for families who have children with disabilities.

Families did not choose to identify community members or community spaces perceived as creating a barrier or sense of exclusion, despite each family having had these experiences. Community plays a crucial role in the acceptance and belonging of children with disabilities, therefore, it was vital to engage with these community role players to learn more about the part they play in inclusion or exclusion.

4.9.2 Exclusion criteria

The following groups were excluded from the study:

- Community members who were not identified and recommended by the families in Phase 1;
- community members who were not able to commit to the time frame of data collection in order to support prolonged engagement practices;
- community members and groups already involved in research projects.

4.9.3 Sampling

In order to gain a representative sample, non-probability snowball sampling was used. This is a method for finding participants where one subject provides the researcher with the name of another and so on until the required number of participants have been reached (Cohen & Arieli, 2011). The sample group with this technique grows like a rolling snowball, and allows researchers to gather a representative sample of participants (Sadler et al., 2010). Families interviewed in Phase 1 provided the names of individuals and establishments that fostered inclusivity or created barriers to inclusion. Two individual community members were interviewed. When families in Phase 1 were approached for community interviews, only two families were really able to provide links to their community. This in itself spoke volumes for their experiences of inclusion and exclusion.

Of these two community interviews, one interviewee was the owner of a frequented coffee shop and the other couple were familial relations. Where it was difficult for families to identify community participants, their lack of community and feelings of exclusion came through strongly in their narrative.

4.9.4 Recruitment

Participants recruited in Phase 2 were influenced by the outcomes in Phase 1. I contacted participants telephonically, via social media, in writing or in person; or in partnership with families in Phase 1.

4.10. Phase 2 Data Collection Method

4.10.1 Narrative Interviews

Once families were interviewed, key community spaces were identified where the families felt accepted and included; or where they have felt rejected and excluded. The community members in those environments were then interviewed in order to gain more insight into the creation of environments of belonging and inclusion and why those particular environments stood out to the families (Appendix B). Participants preferred to share spaces where they were included rather than excluded which guided the interviews in Phase 2. Therefore community narrative participants were selected based on where families felt included.

4.11. Phase 3: Generating a Practice Framework

In this phase, a workshop was held to discuss current practices with other professionals, community members and parents who were willing to share. By sharing the narratives obtained in Phase 1 and 2, the hope was that therapists would be inspired to re-think what their role is within community. Workshops have been proven effective as a method of generating data (Ahmed & Asraf, 2018a; Ørngreen & Levinsen, 2017). They are designed to prompt reflection and innovation and allow participants to be active meaning makers throughout the process (Chambers, 2002; Mustonen et al., 2006). It was a helpful method to enact decolonial practise as it included critical reflection and supported the power imbalance by setting up as a space to learn together (Ndlovu-Gatsheni & Chimbati, 2013; Susana Caxaj, 2015).

4.12 Participants

4.12.1 Inclusion criteria

Community members who had frequent experiences with persons with disability, and parents who were willing to share their stories at the workshop, were included in the study. There were no community members who were able to attend the workshops. However, this was not detrimental as the participants were able to discuss the triumphs and pitfalls of community openly and freely.

Professionals such as SLPs, occupational therapists, physiotherapists, and audiologists interested in discussing current practice were included in the study.

These community members were vital for the co-creation of knowledge around acceptance and belonging as well as gaining insight into the logistical, cultural and social barriers that exist between families and communities and therapists and communities (Jull et al., 2017).

4.12.2 Exclusion criteria

Community members, parents and therapists who were not able to commit to the time frame of data collection in order to support prolonged engagement practices were excluded from the study.

4.12.3 Sampling

The sample in Phase 3 was largely decided upon from the data collected in Phase 1 and 2. Due to the nature of the study, all participants could not be determined beforehand. However, purposive sampling in this phase was useful in order to recruit workshop participants (Campbell et al., 2020). Participants were identified and included in the study as their importance became apparent through the data collection process in phase 1 and 2 as interviewees highlighted key community role players and professionals willing to engage in this discussion.

4.12.4 Recruitment

When considering workshop participants, Phase 1 and 2 were helpful to inform attendees. Interview participants in the community who showed a proclivity for critical consciousness about social issues were approached in person or via social media (WhatsApp, Instagram, Facebook etc.). Professionals were also recruited based on their willingness to engage in the topic and participate in the workshop.

4.12.5 Phase 3 Data Collection: Community and Therapist Workshop

In this phase, once all the family and community stories were collected and analysed, a workshop was held with key stakeholders: families, community members, persons with disabilities and therapists. Recruiting at this stage was difficult — especially when it came to persons with disabilities who used AAC to communicate. While I know the incredible importance of including AAC users, I was not able to include any of these individuals in the study due to difficulties with recruitment. This is a significant limitation of the study. Several emails were sent to individuals with disabilities who were known to the research team with promising response, but follow ups and scheduling proved tricky.

As the study developed, the focus became centred around the burden of communication for families who had children who are or have been AAC users. This became the perspective that I focused on. It would still have been incredibly meaningful to have an AAC user in the study to share their experiences of being out in the community, and it is still a limitation. Additionally, attending the workshop as a parent or community member was an added time requirement as these participants had already contributed in interviews. At this workshop, synthesised research stories of acceptance, belonging and inclusion were shared with practicing therapists. After this, a discussion was based around current SLP practices within communities and changes that should be made with regards to community engagement. It involved critical engagement and created a reflection process around practice and concepts of inclusion and belonging

4.12.6. A Critical Collaborative Workshop

The workshop was a powerful tool for data collection and, at its core, followed the key concepts below.

1. **The workshop was convened to engage and involve critical participants:**

   In order to develop the most effective and beneficial programme, communities and SLPs need to engage in critical discussions and joint problem solving. This required a combination of creative and innovative methodologies to reach the desired outcome and solve multidimensional problems (Budree & Kathard, 2020).

   In order to do this, with the input of the research participants, I created an experience that brought about community-based interpretations of issues and reflective analysis as individuals and as a group (DiSalvo et al., 2008).

2. **It used several critical engagement techniques to create accessibility and participation:**

   Using innovative methods can be helpful in shifting the power dynamic away from the typical researcher and researched relationship (Chambers, 2002). Arts based methods particularly allow participants to co-produce knowledge information which is the core of this study. In addition to this, it allows the researcher flexibility to use different artistic mediums to produce data based on the group created through the use of snowball sampling (Segal-Engelchin et al., 2020). The co-production of knowledge in groups that have been considered marginalised has proven to be an effective way to help professionals outside of the culture, understand and process lived experiences from within (Narhi, 2002).

In doing so, this form of research can provide solid foundations for creating interventions, frameworks and policies that align with that specific group ad their needs (Segal-Engelchin et al., 2020).

3. **It was co-facilitated:**

Workshops can be powerful tools for growth and innovation when harnessed appropriately (Kuo et al., 2017). In order to ensure that workshops can serve as instruments for problem solving, group decision making and connection building, input is needed from more than just a single facilitator (Mustonen et al., 2006). When a workshop is co-facilitated, it allows for different perspectives, identifying pre-conceived ideas before they influence the outcome of the workshop and experiencing different approaches (Mustonen et al., 2006).

Figure 4

Outline of the Critical Collaborative Workshop

4.13. Research Procedure

4.13.1. Family and Community Interviews

The interviews themselves worked much like a set of gears (as illustrated in Figure 5). While it was a process to be followed, activating one phase helped access the next. When families were interviewed together, there was a subtle shift in the formality of the interview to what felt like more of a conversation. The participants were able to draw on each other to navigate past experiences and to build a picture of the future. It added rich data to the concepts of inclusion and exclusion where opinions differed and discussions could be had around this.

In order to connect meaningfully and engage the participants, the narrative process was loosely organised into four stages per interview.

1. **Introductions, building trust and explaining the research:** In this phase, the researcher spent some time explaining the background and purpose of the study as well as build rapport with interviewees (C. Anderson & Kirkpatrick, 2016). Time was also spent assuring the participants that there were no right or wrong answers and that the focus of the interview was to understand their experiences, whatever that may look like. The power dynamic was a bit more manageable to shift as the researcher was known to the parents. Relationships were built over time first, so when it came time for the interview to take place it was possible for families to switch their view of me as a therapist to seeing me as a learner.

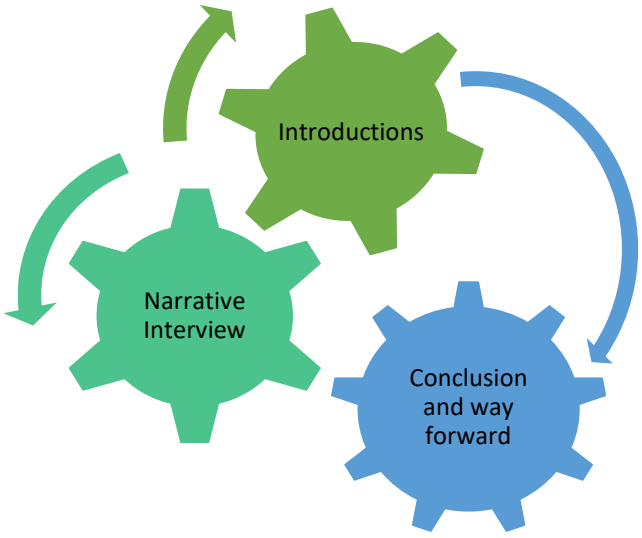
   The time and venue for the interview was chosen based on the advice of the family whether it was at home, at school, online, in person, after work or on a weekend. There was flexibility for when and where the interview took place to set families at ease.
2. **The narrative interview:** At this point, I made use of non-verbal cues to indicate engagement, such as smiling and nodding while encouraging the interviewees to tell their stories openly and freely (Collier et al., 2015). Families were given the option of being interviewed separately or together; and in families where only one parent wanted to be interviewed, this was accommodated. There was flexibility with regards to what family looked like for them and who wanted to participate. The interview was guided by a set of open-ended questions relating to the family, their experiences of having a child with a disability, incidences where they have felt included, incidences where they have felt excluded (if they wanted to share) (Appendix B).

   The nature of the questions also allowed for the shift from traditional impairment-centered narratives to ones that were focused on inclusion. The interview, though guided by the schedule of predetermined questions, also moved organically and families were allowed to follow important tangents related to their experiences. Where they needed redirecting, this was done with follow up questions.
3. **The questioning phase:** Here, I clarified concepts by using open-ended prompts (such as “can you tell me more about…” or “what happened before/after?”) (Fleischmann, 2004). This was open-ended and continuous. In Figure 5 below, this phase is represented by the arrows that ensured the gears of the process kept turning.

4. **Conclusion and the way forward:** I brought the interview to a close while outlining the next steps such as transcribing the interview, scheduling follow up interviews if necessary, how to submit reflections to the researcher post interview and constructing the narrative itself (C. Anderson & Kirkpatrick, 2016).

Figure 5

Representing the non-linear, active process of completing the narrative interviews.



4.13.2. Collaborative Workshop

1. **The workshop was convened to engage and involve critical participants:**

   Key role players such as SLPs, occupational therapists, physiotherapists, audiologists, community activists, non-speaking neurodivergent advocates, parents, siblings, and other individuals identified as being agents of change in Phase 1, were invited to participate in the workshop. Participants in Phase 1 and 2 shared their stories that were synthesised with their consent. They had the option of consenting to tell their story in person or have their story shared on their behalf. The stories were used as moments of learning with regards to inclusion and belonging. There was a focus on communication as well as one of the themes that fell under the umbrella of inclusion.

An analytical story was shared with reflection questions around practice and community which participants in the workshop had the chance to look over and answer beforehand. Sarah, a co-facilitator and parent participant, also shared some of her story and it was an insightful experience to hear the reflections of the professionals who were deeply moved by just the one story — imagine if there was access to hundreds more!

The story formed the foundation of the learning and served as a springboard for discussions around community and inclusion. Once everyone shared their reflections, there were predetermined narrative questions that were asked, guided by myself and Sarah, in order to unpack what inclusion means and how we get there as a society with a segue into how we carry some of that responsibility as professionals.

2. **It used several critical engagement techniques to create accessibility and participation:**

   One of the co-supervisors was in attendance as the graphic harvester and was noting down themes and strong visual images that came through from the discussions during the workshop. She made rough sketches and plotted images throughout the conversation and put them together at the end of the workshop. Audio recordings were used in order to capture the nuances of the interactions between the workshop participants, and to capture reactions to hearing stories from parents and community members for analysis (Garcez et al., 2011).

3. **It was co-facilitated:**

   Before the workshop, I met with the co-facilitator to discuss the agenda for the workshop and order of events. The co-facilitator was given a copy of the research aims and objectives to help guide the discussion to answer the research question. As a parent participant, the co-facilitator was asked to share some of her family's story as a way to frame some of the discussion questions. Her involvement was also crucial in helping the professionals to shift their learning from working with the parents to working with the community. She did this by highlighting the experiences in her life where she felt burdened by the help she was getting, and how much it meant for her in terms of inclusion where she felt she didn't need to use her own skills and knowledge to educate others.

4.13.3. Data Collection Setting Phases 1 – 3

The interviews and workshops were conducted in private rooms, offices or in homes if interviewees preferred. To minimise the risks of COVID-19 infection, interviews and workshops were conducted in well-ventilated rooms with adequate space for social distancing. Where appropriate, interviews were conducted in private outdoor spaces (e.g. enclosed gardens in homes).

I am fully vaccinated and kept my mask on at all times when I was required to. Where interviews required travel, participants were compensated appropriately for travel costs. If the interviews occurred online, participants were provided with data to complete the interviews required. This was only required in one instance.

4.13.4. Data Management Phases 1 - 3

4.13.4.1. Data Capturing

Once the audio narrative interviews were collected in Phase 1 and 2, they were transcribed by myself or research assistants and, from there, stories were created by turning the raw data into a narrative that includes the original content and intent but that were accessible to workshop attendees in Phase 3 (Dibley, 2011). In Phase 3, the audio and visual data from the workshop were analysed (this included the illustrations from the graphic harvesting process).

4.13.4.2. Data Storing

The audio data is stored on an F: Drive on my personal password protected laptop and will be deleted after 10 years as per UCT's Research Data Policy.

4.13.4.3. Training, Expertise and Interpretation

- As part of the PhD study I took a special interest in learning how to facilitate the data collection methods included in this study. Supervision was provided by experienced data collectors in these fields to train me.
- I also undertook fieldwork training regarding reporting abuse and neglect when conducting interviews. As per Section 110(1) of the Children's Amendment Act, if abuse was suspected, it would be reported accordingly (Hendricks, 2014). Should abuse or neglect have been suspected, I would have discussed this with my supervisor in order to find a way forward.
- All consent forms and recruitment flyers were translated into Afrikaans and isiZulu. If interviews were to take place in a language other than English, an interpreter would have been used to conduct the interview. All participants were happy to conduct the interviews in English.

4.14 Data Analysis

4.14.1. Data Analysis Level 1 (Phase 1 and 2)

In order to effectively explore the interviews, the data was analysed to investigate core narratives using Narrative Analysis (Riessman, 2005). This was key to supporting a decolonising research process (Landrum et al., 2019; Sium & Ritskes, 2013; Susana Caxaj, 2015; Tusasiirwe, 2022; Tuwe, 2016). It is common in research to use complicated ideas and fancy words, the stories were here to undo this and allow the research to be accessible (Acton, 2023).

The interviews were transcribed and reviewed in conjunction with any additional information provided (such as post interview voice notes or texts), the transcript, and the audio/visual recordings in order to gain a holistic understanding of the interview (Polkinghorne, 2005). I listened to the interview recordings and read the transcripts multiple times in order to familiarise myself with the data.

After this, key points of inclusion or exclusion were identified for use in the analytical stories. Narrative composition was used to configure the interview by means of transforming the plot and key points mentioned by families into stories (Holley & Colyar, 2009). What developed were in depth analytical stories that were designed to answer the research question and link with the study aims.

The general flow of the stories started with an introduction to the families and then highlighted key moments in their experiences where they felt included or excluded. Community narratives were then integrated to add in support of these concepts with further discussion around inclusion and belonging.

Using a narrative voice was critical to the creation of the stories as it defines the point of view and sets the tone for the story. It is also vital for how the reader experiences them. The narratives were written from a third person perspective, This seemed the most appropriate for the study given how they would be perceived by the audience of therapists' post analysis, and the need to present the stories cohesively at the workshops (Browne & Millar, 2016). Additionally, the story used third person voice as there were often multiple views and voices that needed to be woven together. Given the nature of the stories shared, I felt it would be inauthentic to write from the first person given that these interviews were just snippets of the families' lives and there was not enough depth and background to write it from such a personal perspective.

Setting up the narrative as a vehicle to tell their stories rather than claiming it, or telling it on their behalf, was part of addressing the power imbalance. It was a privilege holding space for these stories. The omniscient nature of the narrative allowed me to relate the thoughts, feelings and experiences of more than one person which was crucial to the flow and significance of each story. It allowed me to highlight key points of each story from a research perspective but also keep the family voice intact. Member checking with all participants was used to ensure that the heart of the story remained while still streamlining the narrative (Birt et al., 2016).

The analysis of data took on a life of its own. Once the family narratives were carefully curated, it became impossible to separate the community narratives from them. In order to be able to tell the community story, the family story was needed first. The families set the scene for the search of belonging and inclusion while the community narratives provided insight into how belonging and inclusion are created. What initially started as a separate process, that felt very disjointed and inauthentic, eventually showed that each family was inextricably linked to their community or lack thereof. Having a community or not having a community influenced how these families experience in the world. For a study where this was crucial to highlight, it seemed ineffective to keep them apart. Thus, the community narratives were woven into the family narratives as an end to a long and winding road.

Taking into account that story telling has been proposed as a new way of knowing, it seemed trivial to disrupt the story telling process for the purpose of positivist approval. Though this can be seen as a representation issue, there were key points in some of the narratives where the family voice directly reflected the community voice. If anything, the inclusion of the community voice added to the making of meaning as this study focused on how belonging is key for both families and the community surrounding them. The community voice was inserted into the narratives at key points, rather than woven throughout, to try and limit the challenges with regards to representation.

The distinction of the community voice was introduced in the narrative by stating who the community members were and sharing their stories. Community voices were included toward the latter half of the story once the family story was told.

Storytelling was used a method of decolonial praxis. It was a conscious and collaborative approach to collecting data that liberated this usually hushed community (Atherton et al., 2020; Brunton et al., 2017). It is the hope that this knowledge can be used to dismantle traditional western practices as well as transform and modify the viewpoints of professionals. Storytelling has proven to be a valuable way of knowing what resonates with communities. It challenges the western opinion that these experiences are wisdom to be shared rather than empirical evidence.

4.14.2. Data Analysis Level 2 (Phase 1 and 2)

This initial crafting of the narrative was followed on by a second layer, Level 2: Analysis of Narratives, generating themes across the these stories (De Fina & Georgakopoulou, 2015). While this was used to highlight generalised themes within and across the stories, each individual nuance was considered as well (Burck, 2005). For example, all the families in the story below had experienced moments of exclusion, all had experience with SLP and its limitations. Each experience was different but each outcome was the same: loneliness, frustration, and a hard-fought battle. Analysis will incorporate the effect of the researcher on storytelling and the bias that will influence the process (Dibley, 2011).

4.14.3. Data Analysis Phase 3

The data was presented through the use of graphic harvesting as well as through the process of thematic analysis (Braun & Clarke, 2006, 2014; A. Leonard et al., 2017). Thematic analysis was used due its theoretical freedom, which allows for an in-depth, multifaceted and detailed account of data (Braun & Clarke, 2006). It is a flexible research tool which is important in qualitative research (Guest et al., 2006). Furthermore, thematic analysis allows researchers to perform robust and carefully cultivated analyses while still presenting the data in an accessible way (Braun & Clarke, 2006). However, due to the diverse nature of the participants being interviewed, an additional decolonial lens is needed in order to generate themes. Therefore the colonial matrix of power will be used as a critical lens to approach this thematic analysis (Mignolo, 2007). Each story was so multifaceted that thematic analysis alone was too basic a framework to use when considering the journeys of each family. Graphic harvesting was used to engage members of this workshop and facilitate participation in discussions around community-based practice and community engagement (Hautopp & Ørngreen, 2018). This particular method of data analysis allowed participants to develop an understanding of complex systems and then come up with solutions from within them; a holistic and inclusive approach to problem solving (Anderson & Shattuck, 2012).

The active participation of therapists and communities from the beginning of any practice improvement process ensures they are more likely to become engaged in the implementation later on (A. Leonard et al., 2017). Graphic harvesting was used as a process and a product which means that while it was used as an instrument for data collection, it also created a product that analysed the conversations that took place during the workshop (Haugh, 2018). Graphic harvesting was helpful in sifting through the plethora of information discussed in the workshop. It provided a platform to pick out the key ideas in a novel way and help structure the analysis using visual support.

4.15. Pilot Workshop Reflections

The pilot workshop was a learning curve. The key to using workshops as the method of data collection was the focus on engagement and collaboration and working through belonging and inclusion as a structured community (Ahmed & Asraf, 2018b; Kuo et al., 2017). The workshop was set up in a classroom of a Developmental Centre known to all participants as part of creating an environment of comfort and familiarity. In attendance with me were three occupational therapists, a co-supervisor as graphic harvester and an experienced co-facilitator. The co-facilitator A.R.[4] has had many years of facilitating workshops and panel discussions. This experience was drawn from her role as a senior leader in her church as well as her professional position as Centre Director of the above-mentioned Developmental Centre. The co-facilitation aspect meant handing over some control of a project I had so lovingly curated and it was a real challenge.

However, it allowed space for me to be present and really listen to what the participants were saying and contribute in a meaningful way. I set up the parameters of the workshop, explaining the study background and the purpose of the study while the co-facilitator took the lead on guiding the discussion and asking the prepared questions. It was important for identifying key points of the set-up, the layout and the structure of the workshop for the main study workshop. The workshop was guided by a schedule of questions I had prepared. They were open ended and meant to provoke out-of-the-box thinking by therapists equally entrenched in their inflexible medical model roots by their occupational therapy backgrounds.

The pilot workshop was not racially or professionally diverse with all participants being white, female, occupational therapists.

[4] Initials have been used to protect anonymity

Though the information was still incredibly valuable for the purposes of this study, recruiting participants for the subsequent workshop was then focused on ensuring diversity in both race and profession. It was also a good lesson in time management and setting out the agenda for the workshop. Edits were made to the workshop pack in order to accommodate this (Appendix D). Additionally, a parent was asked to facilitate the workshop rather than an allied health professional as it was important to have this perspective during discussions. As health professionals, we are still breaking the bounds of our minority world-constructed knowledge and medical foundations. A parent perspective was free of these perspectives and more closely related to the concept of community. After all, these were their stories and their experiences.

4.16. Rigour and Trustworthiness

In qualitative studies, demonstrating rigour is essential to ensure that research findings have the veracity and integrity to make an impact and perhaps influence policy and practice in the long term (Hadi & José Closs, 2016). Participating in a decolonial approach was not an easy process. It has been eye opening to see how much of the research process is entrenched in colonialism. From small things like writing in the "researcher voice" when this research has been so personal to the greater unravelling of the profession and how much of colonialism is entrenched in me. When engaging in these processes, there was no standard model of practice or predetermined pathway. At times it felt uncomfortable to operate without a guide, but at others it felt quite freeing diving into the unknown. It was easier to shift into this space when the aim was transformation. Transformation required critical reflexivity and there needed to be innovation and finding other approaches to do so. The process was akin to the rolling of a snowball; slow and small at the beginning, becoming bigger and bolder through the process. It required me to constantly check and monitor the power imbalances that exist, and try to avoid behaviour that may have been colonial in nature (for example, placing the researcher as the expert). Additionally, I also had to be aware of my researcher bias and the influence it would have on the final narratives. It is important to note here that the narratives here are not perfect reflections of the families experiences. They have been viewed through my SLT lens and constructed with the research purpose in mind. The interview questions themselves guided parents reflections on their experiences in order to curate narratives that fit the aims. In moving away from more positivist approaches, different strategies must be considered in order to ensure rigour and trustworthiness.

4.16.1. Credibility (in preference to internal validity)

The use of a variety of well-established research methods mentioned above, such as narrative interview and facilitated workshops, ensured credibility of the study (Shenton, 2004). I had prolonged engagement with the participants in order to build trust and rapport and establish relationships that lead to greater understanding of issues that may have been quite personal (Hadi & José Closs, 2016).

A wide range of participants were recruited from a variety of races, cultures and socio-economic backgrounds. I had frequent debriefing sessions with my supervisors. This helped to broaden my vision and perceptions, and correct the course of data collection and provide feedback on the work that was done as the project progressed (Shenton, 2004). Member checking was also considered as a tool to enhance trustworthiness and check for accuracy of narrative input from participants (Birt et al., 2016).

4.16.2. Transferability (in preference to external validity/generalisability)

With the findings of qualitative studies being specific to a small number of explicit settings, it is near impossible to establish that the conclusions are applicable to other environments or populations (Shenton, 2004). In order to rectify this, in-depth background information was given to all participants in order to explain the nature of the study as well as all the personal and contextual factors that influence the study to reach for representation and not generalisation (Shenton, 2004).

4.16.3. Dependability (in preference to reliability)

In order to address this, steps were taken during the course of the research to ensure that processes were reported in detail via means of a detailed methodological audit trail (Shenton, 2004). This will allow subsequent researchers to repeat the study in the future and allowed my supervisors to ensure that proper processes were followed (Shenton, 2004).

4.16.4. Confirmability (in preference to objectivity)

Confirmability was upheld through reflective process and taking into account researcher bias at every step of the study. I did this using reflective journaling and peer and supervisor debriefing (Anney, 2014).

4.17. Research Ethical considerations

This research protocol complies with the latest version of the Declaration of Helsinki (World Medical Association, 2013).

4.18. Risks and Benefits

There were no major risks to participants of this study. The interviews conducted might have led to participants becoming emotionally distressed. However, a referral pathway was set up in order to mitigate the long-term negative effects of experiencing such emotions. The benefits of the study will not be immediate, but are essential in starting important conversations around community practice. The articles published from the study will also contribute to the discussion. There was little risk to the community in terms of stigmatisation. While their contributions to wellbeing and belonging were highlighted, this was done in a careful and considerate manner.

4.19. Autonomy

Informed Consent was used to ensure that participants were able to protect their own interests and promoted independent decision making (Pietilä et al., 2020). Participants received a consent form that provided all the information regarding the parameters of the interview, their participation in the study and the dissemination of information (Pietilä et al., 2020). Stories were only collected from families and community members who were willing and ready to share them in order to respect the agency of participants.

4.20. Confidentiality

All data was coded and will be stored securely for 10 years on my password protected laptop or password protected hard drive in order to protect the identity and privacy of research participants (Orb et al., 2001). Participants also had the option of using a pseudonym to protect their identity. All of the participants in the family and community narratives agreed to use their full names in the study.

4.21. Beneficence and Nonmaleficence

In order to maximise potential study benefits and minimise harmful effects of the research, potential risks of the study were constantly monitored and assessed throughout. In case of a risk occurring, I addressed this immediately (Pietilä et al., 2020). There were no risks that occurred during the course of the study.

4.22. Justice

Throughout the study, justice was upheld by treating all participants fairly and equally (Pietilä et al., 2020). All members of the relevant population were given an opportunity to participate in an equitable way (Arifin, 2018).

Chapter 5 – Narrative Analysis Level 1: The analytical story

This chapter contains the narratives that have been crafted from the data collected in the narrative interview. Each story comes with an introduction to set the scene of who each family is and then launches into their narratives. Stories were written from my perspective (as explained in the methodology) and include my voice in the build-up and in some of the stories. Each narrative highlights the families' experiences of receiving their child's diagnosis as well as their experiences of inclusion and belonging or exclusion and isolation. Interwoven with each family narrative, is a community narrative. In some stories, these were family members, for other families they were owners of coffee shops, for some they were strangers and for others, there was no-one. Each story highlights every family's pathway but a lot of the stories converge in themes that will be discussed below.

Story 1: Introducing the Rogers

The Rogers are what you would consider your ideal family. Mom, dad, boy, girl, two dogs. You can almost picture a white picket fence. They are tight knit, have an active social media presence, trade in screen time and pizza. Gary is a dedicated family man — an optimist who is deeply cerebral with the most sparkling wit. He forms the foundation of the household with his wife Sarah. I have worked closely with Sarah in my capacity as SLP since the time I first met their son Oliver (or Ollie as he is known to me). Sarah is sassy, fierce, and entirely unapologetic about who she is. In short, she is a powerhouse of a woman. She is a millennial dream — she drinks coffee by the gallon, loves a good meme and is funny as heck. As such, this story is written in a way that reflects both Sarah and Gary's sense of humour and millennial essence.

Their oldest child, their daughter Calla, is a redhead who lives up to the best stereotypes. She is feisty but incredibly graceful. She is Ollie's friend, sometimes baffled by the double standards that exist between them as siblings, but she is always ready to protect her little brother.

And then there's Ollie. A blue eyed, golden haired little firecracker who is willing to take on the world (as long as he is well fed). Ollie was born with Down syndrome, brought into the world facing adversity, yet he has never stopped fighting. He loves the cartoon *Captain Underpants* and his favourite pastime is spinning a pair of underpants around his finger. He loves singing along to any and all Disney/Pixar songs and is an avid Swiftie[5] (something the two of us have in common). In the last three years of our relationship, whenever I saw him, I was required to sing at least one verse of Taylor Swift's *Shake it Off* before moving on. We've probably performed an entire concert together!

I first started seeing Ollie for speech therapy when he was about three years old. He could say about five words and sign a few more. Their family goal was to get him talking, my SLT goal was to get him signing — so we ended up meeting in the middle. With regular input, Ollie's language usage improved, and he started using sentences to communicate within approximately three months.

[5] Swifties are the fandom of American singer-songwriter Taylor Swift.

Sarah still credits me for helping Ollie find his voice and to be perfectly honest, I cannot agree. It wasn't imposter syndrome as much as it was me recognising that I did very little work — outside of the 30 minutes a week that we collaborated on his goals, the other 167.5 hours of the week the work was done by his family. We did therapy through music because Ollie loved song. The weekly half-an-hour session we spent sitting on the floor singing songs about animals and buses were some of my fondest. There were times where Ollie would stealthily escape from his classroom and show up in the therapy room, at his school where I worked, demanding we sing *Old MacDonald*.

Even today, I can't walk past him at school without singing a verse of *Shake it Off* for fear of risking him pouting. In our sessions Ollie's parents and I learnt how to pause, slow down, and how important it was to give him time to communicate and acknowledge his non-verbal cues. We played with bubbles and learnt the Makaton sign for "more".

This relationship made me realise for the first time that I was not the expert, it showed me the cracks in my Alternative and Augmentative Communication (AAC) because other than Sarah, there was no one else to sign Makaton with him. Their community was everything to them and I was only one small cog that was turning one small mechanism. This relationship was key and ignited the spark in me. My interview with them highlighted the isolation they felt at first because of how difficult support was to come by. It highlighted the fight they undertook as a family to find Ollie places where he could belong. Despite the stares and the judgement and the utter ignorance of some, they made it.

The Rogers Narrative: Are You Ready For It?

When I think of the Rogers in the context of Ollie, I think of the idea of relying on dictionary definitions, which can sometimes come with negative connotations about authenticity and originality in how they're used in wedding speeches, as an example. There are so many dictionary definitions that this family both lives by and reinvents. Sarah, Gary and Calla live their lives as dictionaries for Ollie — it may not be something they do intentionally but it is a mantle they have taken up as his family. At any given moment they are translators, describers, code-breakers, secret keepers and comforters for this remarkable little human.

When stepping into the Rogers household, you are always welcomed by the background noise of Disney. Whether it is Ollie belting along to *Moana* or sitting folded like a pretzel falling asleep to *Coco*. In Hawaiian, "ohana" is the word for family. In the Disney film *Lilo & Stitch*, a story about a young Hawaiian girl who befriends an alien, they offer the definition for "ohana" as: "Ohana means family. Family means nobody gets left behind or forgotten" (Lilo & Stitch, 2002). It is a definition of family that resonates with me. It is deep, true and speaks to a need for belonging; and I am strongly reminded of this concept of family when I am in the Rogers' presence.

Ollie was born under the haze of bright lights and the clinical calm of a hospital. While Sarah was pregnant with Ollie, at their 20-week scan, his parents were told that Ollie had a one in 200 chance of receiving a Down syndrome diagnosis. It was a shattering truth that sat between Gary's optimism and Sarah's realism. Though, having had Ollies older sister Calla a few years prior, Sarah already knew that something was different about this pregnancy. Her intuition told her so. Two hundred is a big number, but it pales in comparison to millions. Only after Ollie was born did they come to terms with the fact that one in 200 is a big chance of Ollie being born with Down Syndrome when you consider the roughly eight billion people on the planet.

Ollie was born with a pneumothorax (a collapsed lung) that was cloaked in panic and uncertainty but Ollie is a fighter. He was whisked away at the behest of the doctor for lifesaving treatment. When Sarah and Gary finally got to hold their son, he was handed to them heavy with the weight of his Down syndrome diagnosis. And then the doctors were out. Medical Ghosting at its finest.

As the Rogers family navigated this new path for their son, there was an expectation of support. A rally of troops which is listed here: FAMILY, Midwife, Church, Google, Occupational Therapist, Down Syndrome Association and then…the sobering truth. The list of support ended in: “We lost some friends along the way”, Nothing, No-one, Sorry, This is awkward, Bye.

You could say that support was hard to come by. They say that it takes a village to raise a child, but nobody tells you where to find it. The journey after they received Ollie’s diagnosis was cloaked in uncertainty and with no clear direction. Sarah, looking for new information, found herself going down a Google spiral that led to a plethora of doom scrolling. She reached out to medical professionals and Down Syndrome Association SA and while there was an abundance of information around the diagnosis and the challenges, there was nothing on how to raise a child with different needs. It seemed as though every organisation had their own agenda, and none of those agendas included working together or with the families at their forefront.

Sarah went on to say: “There was none. There was no support from the medical professionals. I am a researcher by nature, not only in occupation, but like just generally. So I didn't even know there was a Down syndrome association. I have a vague memory… I think maybe the hospital sent them my details. And I met with the lady there… she was semi helpful, to be kind. Semi helpful. There's a lot of politics in that space. And everybody was a bit jostly [sic] for, like, ‘I want the Down Syndrome Association to go this way and that way’.”

The politics seemed more important than trying to help this family find their way.

There are many ways in which Sarah and Gary have steeled themselves against the world. They have armour for the stares and the questions that follow them wherever they go. Sarah recalls as if it were yesterday, the first time she had to put her armour on to shield her son from judgement. It was a fairly innocuous day on a family trip down the South Coast of Durban.

They were a new family on holiday just trying to decompress and get away from the stress of the world. They stopped to stretch their legs and get a snack at a tiny hole-in-the-wall restaurant where Sarah could feel eyes on Ollie the entire time. The table next to them ogled Ollie as if he were from a distant planet.

They said nothing, but the silence spoke volumes. For Sarah it was a defining moment as a mother. There were two options: either let it go or do something about it. Sarah went with the latter.

She put herself in front of her son and asked the staring people if there was a problem. Like most cowards when confronted, they slunk back in surprise and vacated the premises quickly. It was not the last time Sarah would need to come to Ollie's defence, but it was the first lesson for her in learning to pick her battles. Sometimes she has energy to fight the stares. Other times, she needs to save the energy to fight the questions:

"Why does he look like that?"

"Why can't he talk?"

"Why does he sound like a baby?"

Don't get me wrong, the Rogers love when you ask questions. They find being responsible for educating those around them both important and exhausting. They are mindful about how much they take on but at their core, any questions asked that allow them to advocate for Ollie are the ones they are the happiest to field.

It is a double-edged sword because questions mean opportunity but silence means peace. It has been a hard-fought battle for the Rogers to find a balance.

Nestled in the heart of Durban North is a coffee shop. A quiet unassuming place made of glass and sunshine. On most days you can find Ollie here, sitting cross legged in the middle of the thoroughfare or perched on a stool as an honourary barista. If you listen long enough, you will hear him try and weasel another "peezo" (Freezo – one of their signature frozen beverages) from an unsuspecting waitress charmed by his smile. Unfortunately, they're on to him. All requests go through Sarah and he is left disappointed by the lack of sugar in his life. In this coffee shop is what the Rogers think of when they think "community". Community is freedom. It is not having to explain, to be known and just being allowed to be. There are no stares when Ollie is having a bad day and doesn't want to greet anyone or feels the need to growl in frustration. There are no questions when he is singing to *Moana* behind the counter. Here, he is Ollie. He is not a boy with Down syndrome or struggling in math.

For Sarah and Gary, this is a space where they get to share what they want and let go of what they do not. There is a sympathetic ear when Ollie has been up at 3am for the fourth time that week (with the bonus of free-flowing coffee). There are ululations of joy when Ollie has reached a new milestone. There are quiet affirmations and encouragement and the good kind of questions that let the Rogers know there are people who are there, showing up for them.

The owner first met the Rogers at church. Her spiritual and personal morals are centred around truth, offering support to those who need it and loving those close to her. She says this: “Every moment, every morning when you wake up, we actually have a choice to be kind, joyful, peaceful. We have a choice and we can grab it. But it has to be your choice.”

The owner of this little sanctuary is a bold and vibrant woman. To her, inclusion was not even a second thought as it is rooted in kindness. “We need to be more honest, be more supportive. Like I said to Sarah in one of our first conversations: ‘the reality is that when we get pregnant, the first thing we pray for, or we hope for, or wish for is that that child is 100% perfect in what we think is perfect. You know, 10 fingers, 10 toes, no disabilities’. The big Down syndrome, you don't want to hear that. That is not the word you want to hear. And then you hear it. And then you’re like, what does that look like? Because Sarah and Gary’s life looks completely different from my life. And so we need to be supportive, we need to be understanding, and we need to love them even more than you love others. You know, that's my feeling. And so yeah, we allow Ollie to sit in the middle of our coffee shop, on his iPad. On the floor. Cross-legged. It's an absolutely incredible skill the way he sits, if I can be honest. Honestly, we all need those kinds of skills, you know what I’m saying?”

She laughs and shakes her head knowingly as she pictures the way Ollie wraps himself up like an Olympic level gymnast. Of Ollie’s role in her business she says: “He sits at the back and my staff know that he wants a ‘Peezo’ and the ‘Peezo’ is a Freezo. And we know when he’s asked for this, just make sure Sarah has said yes to that because that is a staple. But the only way we can be accepting and loving of people is just to be a little kinder. And actually, I think kindness does mean asking hard questions.” When she thought the Rogers were ready, she came with questions like: “What is it like to have a child with Down syndrome?”. It gave the Rogers space to explain their reality but also to celebrate Ollie. And so began the start of a beautiful friendship and the locus of inclusion.

When Ollie was first diagnosed, Sarah and Gary bounced around from organisation to organisation looking for answers. Sarah waded through medical opinion, through being told to “wait and see”, and through the politics of organisations that were less than helpful. Call it luck or divine intervention, but their path was lit by the random meeting of a stranger who would change the course of their lives. Sarah is unclear on the details but through a friend of a friend, she received a phone call from the director of a Developmental Centre who wanted to meet her and hear their story. Through this single connection, a web more intricate and supportive than anything they could have imagined was created.

They found professionals who would see Ollie without just “waiting and seeing”; therapy that could start before he was one year old; and they found a centre where they were provided sanctuary. It is rare for lightning to strike twice but, for the Rogers, it did. These bursts of light have remained their safe spaces. As warm and beautiful as this sounds, when you zoom out and look at their lives, they are two small islands of hope in a wild world that still, for the most part, leaves them feeling othered.

For Sarah and Gary, being in the presence of others is a sobering thing. Sometimes just being in spaces where you are included can be alienating for them. On the one hand, they feel welcomed when they are invited to parties and playdates but, on the other, their differences are only highlighted around others. It’s the moment when their bubble pops. The “Oh, so *that’s* what normal is” moment. They watch their nine-year-old son prefer the company of the four-year-olds as his disability is laid out in front of them. On a good day for Ollie this gap seems small but, on a bad one, the reality is stark. Sometimes the quiet sinking in of reality is worse than the questions and the stares.

Gary says: “There might be some norms, but because they are so small and your norm might be different to somebody else. So you don't... It's very difficult to… I don't know, you try not to compare what your kid is doing to the next but it's that constant assessing of what does my child need now to suit him best. And it's that extra layer of being cognizant of what you're doing and what needs to be done for him.” The developmental clock is always ticking, like a Tell-Tale Heart.

After many wrong turns, redirections, and shouting into the void, they managed to catch a glimpse of their village, piece by piece like sunlight through the forest. Soon they were dazzled by the bright spots of belonging that were created just for them. Coffee shops, supermarkets, schools.

Once, Ollie went to the supermarket and fell in love with some chicken nuggets. He refused to part with them, his little fingers turning just the slightest shade of blue from the ice. The cashier behind the till was patient, kind, understanding. She showed Ollie how she swiped the other groceries through.

And eventually, she got him to agree to let them go and wait at the end for them. He beamed at her when the transaction was complete. And Sarah let out the big breath she had been holding. This woman who showed up for this boy she didn't know was a shining light in the Rogers' journey. They visit that supermarket regularly now. It wasn't in that employee's job description but she was a champion of inclusion and belonging.

Belonging captured so beautifully by Ollie's popstar hero Taylor Swift in her song *Shake it Off.* As a family, in these pockets of calm and chaos, they could shake it all off and just be who they are.

Story 2: Introducing the Da Canhas

When I first met the Da Canhas, Tate was the tiniest little lad. He always had a car tucked firmly into his little fists and loved to do things his own little way. I say little, because that's exactly what he was — little. At the tender age of two, Tate was diagnosed with autism and it spun his parents' worlds on their axes. We met shortly after this. Debbie is Tate's mother, one of his best friends, and a woman deeply marked by this journey of autism. Jono is Tate's father, his anchor, his protector and where needed, his wrangler. His older sister Hannah, his companion and his benchmark.

The journey Tate and I walked together was a defining moment of my career. In all honesty, as a freshly minted therapist, the thought of him struck me with fear. Fear on a personal level because I didn't want to bitten (again) and fear on a professional level because I did not know how to help him. My job was communication and this little boy seemed trapped by his inability to do so. He was non-speaking but had so much to express.

In saying this, the use of visuals unlocked a door as Tate was a visual learner. Then came Makaton. I had just done the Makaton course and thought it might interest him. Firstly, Tate was fiercely independent and using the Makaton method meant that he didn't need anyone else to help him communicate in the way that he did if he used the Picture Exchange Communication System (PECS). Secondly, he had learnt so well through visual support so I believed that he would be able to communicate visually. I made his family a video of key signs to start off their practice and soon Tate was hunting me down at school on the playground, in my office, and in neighbouring classrooms just to perform these signs with me. There is a video of Tate and I performing Makaton together that his teacher covertly took of us and it remains a memory of one of my top three moments of being an SLT. In the video, you can see Tate and I engaging, really engaging, and becoming absorbed in each other. We practiced our signs together and watching him choose his communication style and develop agency was a huge, shout-it-from-the-rooftops experience. And I have not stopped wanting to shout about it since!

To this day, autism remains a thorn in the Da Canhas side. A constant barrier to their dreams for their son and a shadow over the future that becomes an all-consuming fear. Despite his success, growth and unbelievable tale of overcoming adversity, his autism still binds him to a fate that neither Debbie nor Jono wanted for their only boy.

This story reflects their inner turmoil woven with the metaphor of a storm. Storms come and go, they rage and mellow; a law unto themselves. When you catch them just right, they are beautiful. This whole journey has been a series of storms for the DaCanhas. And they have surrendered to each storm, waiting for those moment when the it passes and they get to see the stars.

The DaCanha's Narrative: When Lightning Strikes

When Tate was two years old his mother Debbie saw an article in the newspaper about autism — talk about fate. As she read, her heart started to sink. It sounded like this newspaper was describing Tate to a tee. His love for lining up cars, the way he always seemed to be happiest on his own, the way he experienced the world differently to their daughter Hannah. Tate and Hannah were not born that far apart and for Debbie and Jono, they knew very deep down that something was not quite right. There is a great deal of trauma that sits with these parents around Tate's diagnosis. Debbie said baldly that her "world fell apart", but at the same time, having two babies so close together, the differences were glaringly obvious, she knew but she also didn't want to confirm her suspicions.

When asked about their journey with autism, Jono and Debbie answered at the same time. They looked at each other as Debbie said: "I think the first few years of autism were just absolute [J: chaos] hell. It was so hard." It was chaos and hell. Debbie went on to elaborate by saying "he was non-verbal. And it was… communication was hard. And dealing with two young kids was hard, trying to show Hannah love and attention when your brother was just screaming at night. That whole time was just an absolute mess." They were being pulled in so many different directions, it was only a matter of time until something broke. And they nearly did. Jono reflects on that time: "Tate was so demanding. Bedtime he's demanding, morning time he's demanding. You have to do everything for him. So all of that was kind of like a culture shock. It's a family shock. And it's a personal shock that you have to kind of get through.". They both seem to describe that time with a bit of PTSD. Glazed eyes, surviving on coffee, constantly in fight or flight mode.

After Tate was diagnosed, he was eased into a group learning environment to start his early intervention. When Tate first started school he despised it. As most three-year-olds might. What a tumultuous time it was. It was months of screaming, biting, hitting, crying, cuddling, loving, appreciating; this was his form of communication. This was him letting everyone know what he liked and what he didn't like. He was a storm in a teacup. Sometimes, his mom says, she still hears the echoes of his screams as she walks through the corridors. He was frustrated, and we all bear scars from his bites of frustration. For Debbie, communication was definitely a tender subject and it was the most mundane interactions with her son that she craved but never got.

“Normally a boy, young boy at the age of four would go: ‘oh look, there's a truck’ or ‘I'm seeing a forklift’ or whatever. And he never spoke. He didn't say anything. And so driving to school was always so hard for me because I couldn't talk to him. Even though I could. I wanted to… he would see things, but he wouldn't do anything about it. And even the words ‘I love you’ was like…he just never said I love you,” she said.

As soon as Tate found communication, the screams quieted, and this amazing little human’s world just opened before our eyes. It was met with disbelief and trepidation. Even progress was difficult. “The defence mechanism [in navigating his progress] is [having] no expectations” Debbie said. When they did find support they remembered, with fear and fondness, what it felt like. “It does bring a tear to the eyes. You think back here. Yes. We were almost dying. Like at that time. It was really hectic.”

When they got to Khanyisa Developmental Centre, “it was like a ray of hope, because there was such knowledgeable support there. And caring! People going, ‘we get you, like we understand what you're going through’. Because we were only Debs and I and we thought no one will never understand what we've been through. So to have people who kind of can see into that a little bit and have experience dealing with other parents of other kids on the spectrum or other special needs. There was support there,” said Jono. For the Da Canhas, they found a village who understood. It was more than they could ever imagine. They didn’t have to do this alone anymore.

We all spent hours brainstorming how to support this tiny tempest. We replaced the biting with a chewy, but then he started climbing the window bars. So we put up curtains. And then he started hitting his peers. Every time we put something in place, something new would arise. It is the unspoken hydra of autism — there is always something else. Then we taught his parents Makaton. The technological marvel that he is, Tate started watching those Makaton videos and every day, he would find me to practice those Makaton signs. Soon he started attaching meaning to those Makaton signs. Once he started attaching meaning to signs, he started attaching meaning to visuals. It was magic watching him initiate a skill that would catapult him into progress.

We moved on to PECS after this. I was young and guided by my mentor at the time to ease him out of his frustration using this system. It was a harrowing time back in 2017. It was a few hours a week in an empty room with myself and my mentor trading pictures with Tate for cars and swings and all the things he loved. There was a lot of screaming involved. Tate did not want to be there and neither did I. But this was intervention. It was evidence based and it was a staple of any speech therapist's toolkit at the time. He initially struggled against the hand-over-hand approach and then he didn't, and I still wonder how much of that method broke him. It worked but I know different now. And in that I think is the crux of our profession: to know better, do better, and never stop learning. I wouldn't use it again, but at the time it was a key that unlocked so much potential in Tate. But even still, his progress balances on a knife edge. His parents are still holding their breaths. Still living in fear that it might just all disappear in a flash.

Cut to present day, Tate has an incredible eidetic memory that makes him a ferocious reader. He loves a good joke. He frequents restaurants with his family and goes on holiday. He's a musician in training and my goodness does he have an ear for a beat. He still loves cars, but now he loves planes and helicopters too. He loves trying to understand how they work and his dream job would be pilot or musician.

This little boy who loved everything just so, was brave enough to get into a helicopter and go soaring through the sky. He makes excellent conversation and can tell you what he did over the weekend. He has great fun pretending to be a YouTuber. He is reading, he is writing, and he loves drawing. His favourite things to draw at the moment are guitars and lightning bolts. He drew one for me just for this story when I told him I was going to be writing about him.

He loves finding out new things about the world and his place in it. He has just started getting his hair cut by an actual barber as much as he finds it strange and a bit uncomfortable. He glances wistfully at the other little boys at drop off when his sister goes to school, and he desperately wants to be their friend. He wore a tie to school the other day because he sees their uniform and he wants to wear one too. It is still a conversation his parents have to have with him about why he can't be there right now. He is desperate to be included. To be a part of something. They are dreading it.

Of autism Debbie says: “I think adjusting to autism for me as acceptance… I only really accepted it about four years ago. Prior to that I was like, I hate autism. I'm not accepting it. It’s just more like hurt. That that’s the future of my son.”

There are certain trajectories that are marked when you are labelled. The what ifs never stop: “will he ever talk? Will we ever progress? Or will he be like a two-year-old forever? Will he stop hitting? Will he stop biting?”. For the Da Canhas, the unknowns are painful, the uncertainty is an ache they are never quite done with. A secret and lingering heartbreak as they watch their son grow. The future is constantly evolving in the dark.

Going places with Tate is still a source of stress for Debbie and Jono. Even after all this time, they still don’t feel like they can fully exhale. Even though Tate has come leaps and bounds, there is an element of stress everywhere they go and in everything they do. They talk of being hypervigilant, and on the edge of fight or flight, always waiting for the other shoe to drop. Jono speaks of his experience being a “helicopter parent” in order to prevent judgement. Debbie recalls experiencing that judgement from customers at a grocery store as Tate had a meltdown as young boy. The memory has never left her, and it has marked her. She was that parent standing helpless in the aisle while she tried to bottle the storm. She was subjected to stares and judgement and not a single offer of help. It was the first of this kind of experience but it certainly was not the last. It was easier to retreat than to be subject to the humiliation, stress and shame. Jono says, “I’ve never had a moment, outside of the special needs community, where I felt everything’s cool, I can just relax, like no stress. Even going to our church, which was an awesome church, very inviting, accommodating, you still feel stressed, you still have to chase him around. You don't feel at all like you're *not* welcome. But you don't feel like I can just come here and everyone will be understanding.”

Even places where the judgement bar is low, there is still fear of rejection and isolation and being told to leave. For Hannah, she is acutely aware of Tate’s differences. At her morning drop off as Tate stares longingly at the boys he wishes to befriend, he vocalises… loudly. She needs to ask him to be quiet. It is complex and difficult for her to manage these emotions of loving her brother unconditionally and trying to fit in knowing he is different. Inclusion is such an intricate web.

In 2023, when Tate turned 10, he asked to have a party for his birthday. And as much as this terrified Debbie and Jono, they wanted to do this for their son. They invited his entire class — 9 other children in total. These were Debbie and Jono's fellow soldier families. They all knew the struggles and accomplishments of raising neurodiverse children. Every day they donned their armour and swords down in the parking lot, and they were able to destress and confide in each other without carrying the weight of a shield. Even a year ago, Debbie would have said no to an invitation like this had it been offered to her but she had been shown such kindness and lack of judgement in the embrace of these families that it had made her brave. She did not have to always apologise for Tate's vocalisations and quirks that make him who he is. Debbie sent out the invitations hoping she could make someone else feel brave but as the RSVPs started coming as "maybe" and "no", she grew disheartened. This community was a force that welcomed her with open arms and when she extended her own she was met with hesitation and fear. She totally got it. She had been at the place many times herself when the fear won. But she couldn't help but feel a bit isolated, discouraged, and sad that these families she went to battle with daily couldn't fight for this. For Tate. He ended up having the best day with the families who did show up and it was a proud feather in the DaCanha's cap of another milestone that did not defeat them.

Dreaming for Tate is hard. To face the future is something Debbie, in particular, has not allowed herself a glimpse of. At the end of the day, they just want him to feel like he is "achieving within himself" and they want his life to have purpose. Whether that means being in a committed relationship or holding down a full-time job. Sometimes they allow themselves the luxury of imagining Tate as a sportsman (pro-surfer or rugby star) but then they quickly let it go before it is taken from them.

Hope is fleeting like the brightest flash of lightning but it leaves a void in its wake. That light is quick to fade and seemingly impossible to hold on to.

Around him, Tate has a growing community of people who revel in his triumphs and gently pick up the pieces in defeat. In particular, Tate's aunt and uncle who dote on him, are his number one fans. It is difficult to not be won over by him. When Tate was first diagnosed, Tate's uncle threw himself into the search for answers. He combed through Google, he spoke to parents who had autistic children, he made it his goal to understand. For Jono and Debbie, this was a burden they could not ask anyone to bear.

And yet, there were people bearing it. It took the Da Canhas a long time to trust anyone else with an afternoon outing, and then a meal in the outside world, and then a night away together. Last year, the Da Canhas left Tate in the capable hands of his aunt and uncle so that they could attend Jono's Christmas party. They were not 5 minutes away from home when Debbie called to check in and make sure they knew where the gluten free snacks were. The babysitters lovingly roll their eyes but it made clear the anxiety that the DaCanhas still have to this day. It is a cloud on a starry night.

The aunt and uncle have two hands stretched out to assist, offering school pick-ups and date nights, but for the DaCanhass there is so much fear in letting go of their control to grab hold of this lifeline. They are starting to trust, slowly and safely. For them, community is there but accessing it is a constant battle. They are battered and bruised. They have lived their lives ruled by judgement of others, the uncertainty of the future and fear the of exclusion when the penny finally drops and people realise it is too much. They are too much. Tate is too much. Autism is too much. They have built walls to keep themselves safe but, the thing is, is that those walls keep everybody out too.

Debbie and Jono spoke about the nuance of autism being a "hidden" disability and the door that opens for judgment as a parent for not discipling your child or letting them behave in such a way in public. When they say public, they don't mean just places in their community but they mean any place outside of their home. They spoke a lot of expectation. Where this little boy, in the midst of a meltdown, is branded as naughty when really his frustration at not being able to communicate reached a peak, or he was going into sensory overload.

Jono said something interesting that still resonates many months later: "And so we dove into educating ourselves in all of that [autism]. You realise the people around you, just as you were prior to the diagnosis, where they know very little about autism and all that. You can't expect them to just educate themselves and to know all the answers to everything and how to be." You can't expect them to educate themselves. They felt that this was not something they could ask of others. They knew it would make others uncomfortable, not knowing how to handle Tate. It was a messy and isolating thing.

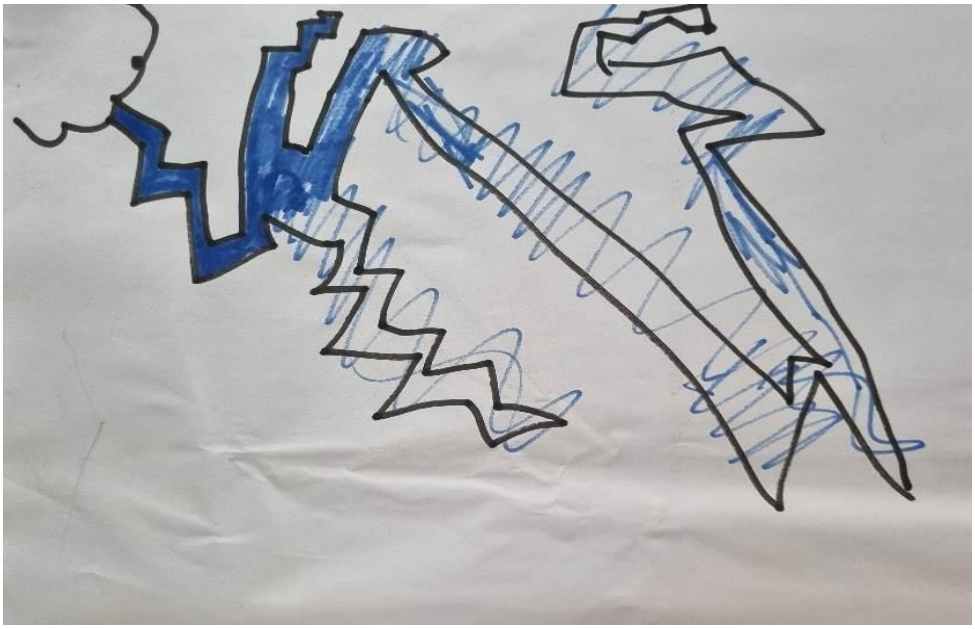
Debbie and Jono have walked a long and fairly traumatic road. They have shouldered a burden they could not seem to share. This is a key reflection that highlights the need for community and connection. What if they felt like they *could* share? What if turning to others for support was accepted and freely allowed? What if the assumption was that the load was meant to be carried by a village? There is so much weight of expectation. Expectations of what Tate should be, of what Debs and Jono should be, of how much they could ask for help and whom they could ask it from.

Expectation was like a monsoon. It rained down all around them, flooding their lives and making simple things very difficult to navigate. It threatened to drown them all over again — as well intended as that expectation was. No one, apart of Debbie and Jono, will never truly know what it's like to be Tate's caregivers, guardians and secret keepers. But in recent years, there has been more support as understanding has grown. There are fewer suggestions of solutions and potions that might act as a cure that others have found on the internet.

Tate is loved and celebrated and, although they see the change, progress and growth in him, Debbie was raw and real when she said that if she could cure Tate, she would in a heartbeat. She would give anything to live in a world where autism didn't exist. She says this as she brushes his hair back and he kisses her on the cheek for the fifth time in that hour. There is so much connection here. They have accepted him for who he is through a journey of blood, sweat and tears. Through the rumble of thunder and the flashes of brilliant light.

Figure 6

Tate's drawing of lightning (2023)



Story 3: Introducing Raeesah

When I scheduled my interview with Raeesah it was going to be a family affair. But on the afternoon, it was just her. Her husband was there with their beautiful son Yusuf (who was born with Down syndrome). Her little baby was asleep in her lap, but it was just her facing the interview alone. I should have known then how much this simple act meant but it wasn't until after the interview that I realized how much she carries on her own. It is always just her. The interview took place at Yusuf's school, a factor I considered when inviting them as a family, so they would be comfortable, welcome and settled. It spoke volumes that, for my sake, they kept him removed so he would not disturb the interview. For me, his presence would have been welcome but for them, they were trying to not be that drop in the ocean that's started a ripple. This is how they live their lives, avoiding the ripple.

I set up activities in the room for him to entertain himself, knowing he is well capable of doing so and that they bring him joy, but his parents wanted to be good participants and so that meant not having him be a part of it. I respected their wishes and for Raeesah's comfort moved everything on to the playground for Yusuf and his dad to enjoy.

Raeesah's interview was shrouded in uncertainty from her ("I hope I'm saying what you want") and reassurance ("everything you're saying is great – there is no right or wrong answer – I'm learning from you") from me. She held back tears on many occasions, from when she spoke about receiving the Down syndrome diagnosis for Yusuf, to how difficult the journey has been thus far. Around her words were a veil. It was as if there was this smoke that curled its tendrils around her when she spoke, growing, thinning, billowing, thickening, suffocating. There was uncertainty, there was isolation and this veil that I could sense — it was loneliness.

Out of all the interviews, Raeesah's was the only one that did not have a community follow up. She struggled to identify her community. There was no person or physical place where she felt she could exhale; where she felt Yusuf could belong. Sure, there were the friendly waiters at restaurants that loved to greet him and she could leave him with her mom for 20 minutes while she whizzed through the supermarket. But for someone who could understand him; wholly, truly, understood his signs, knew that bathroom was a different sound to hungry. It was only her. She found solace with her online community.

A lot of the groups she mentioned were parents or family members of neurodivergent children only and restricted to professionals or outsiders. It was a community that has been created with the safety of the members in mind. I am glad for her. For what she's told me, these internet warriors rallied around her in her moment of need. They answered her questions, they voiced the same fears, they never judged her, she could exhale.

This is a woman I had spoken to about a core board[6] for six months. We'd had Individual Education Plans and trainings and car park conversations, yet here she was telling me that it's actually not her that needs the support. She understands the need for visuals and alternative communication. She knows Yusuf's strengths and weaknesses. But she needs others to know this. She needs his grandparents to know that he's not being lazy, she needs other children know how he asks to play. And where had my focus been? Not there. I put the burden on her again and again, a woman who already carried so much.

[6] a type of communication device/visual that contain core words along with their visual representations

Raeesah's Narrative: The Inclusion Paradox

The fundraiser started at 10am and there she was at 10:01. Raeesah arrived ready to work. It was Mandela Day and the purpose of the day was to give back, pay it forward, and show up for your community. Most people liked the jobs that were easy on the back and the knees, but there was Raeesah huddled in the dirt, gently giving new homes to plants that needed them. For an hour, she tilled the earth and settled each plant into their little sanctuary of soil, sun and water. This was a woman who showed up; for her family, for her son. She arrived alone and she left alone with her aura of kindness and goodwill. It was clear that she would do anything for Yusuf. She is his person and understands his gestures, vocalisations and all the ways in which he communicates — his dictionary and interpreter. She helps him walk and talk when he cannot. She is the encourager, the secret keeper, the dreamer. She shows up for him and then she is gone. She smiles and she makes conversation and is not one to linger. She is there the same way the waves always are at the seaside, but she is variable as the tides. Their life together has been a string of paradoxes of being but not belonging, accepted but not included.

Sitting alone in the hospital it was Raeesah who has handed her baby and his diagnosis. Her she was in this institution of healing and helping, feeling more hurt and heartbroken than ever before (Paradox 1). It was with tears in her eyes that she recalled how the doctor breezed in and out leaving her with this tornado tearing through her life. Her first born, her son. There was no guidance, comfort or hope. Yusuf was born prematurely and she was told he needed to spend time in the ICU. It was only the next day that she got any information: "So the next day, he [the doctor] tells me, you know, the nurse has picked up a few signs of Down syndrome. But we've got to do a blood test to find out. But there was no sitting me down — asking if I know what Down syndrome is. You know, no, explaining it. Oh, just like that. He didn't come to sit down or chat to anything. That's how he told me." It felt like someone had yanked her from the warmth and safety of the soil and planted her in an unknown terrain.

In saying this, the loneliness surrounding her in this moment, Raeesah found comfort in the Cloud, the digital cloud that is. Though she could not identify a physical community in our discussion, it actually sounded like she found one online (Paradox 2). For most, community is a tangible entity. It is a vine growing around the family, sheltering them, holding them up, giving them strength when they feel they cannot stand alone.

For Raeesah, she could think of no-one, nowhere. She toyed with the idea of the security guards at her building who always say hello to Yusuf or perhaps the waitress who was always kind to them when they went out to eat. While they created moments of joy, it wasn't anything constant for her. They were not "her people". And then it came to her.

She highlighted Facebook groups as being a supportive force around her where she was able to access "tips and hacks and all of that, because they all went through the same things that you go through." They nourished her. Having access to mom's experiences around the world helped her through this upheaval and isolation. These groups are protected by in depth security questions and off limits to researchers as one of the measures to shield their members. She shared that the hospital gives you little information if anything when it comes to understanding a diagnosis like this. So "you need to start researching on your own. So actually, the mom's groups helped a lot. Having the mom's groups really, really helped." This virtual support network was a lifeline to her. They might have been thousands of kilometres away but for her they were the connection she needed (Paradox 3).

Through this community she found him a paediatrician who would understand them; she found therapies and a school. She found every service needed for early intervention and did everything she possibly could and yet…(Paradox 4) "other people make you feel like you're not doing enough". She has been plagued by unsolicited advice through all of Yusuf's young life and is learning to shut it all out. Acceptance is a hard-fought battle for her. Despite it all, she has watched him grow and basked in the glow of his progress.

It is all too easy to be won over by Yusuf. He is charming, joyful, engaging, wilful, and determined. He has big brown eyes with perfectly coiffed hair à la Raeesah. His smile is radiant, welcoming, utterly disarming. He is always dressed in the latest of fashions. In this way, Raeesah makes sure he is always ready to put his best foot forward. People are easily disarmed by his bow ties and superman swimsuit (with cape). He loves people. He loves watching them, being close to them, following them. He can often be found on the playground, arms behind his back surveying the other children with curiosity. At times, when he is really interested, he'll do his best to keep up. But it is difficult for him at the best of times.

He is still unsteady on his legs and needs someone with him. Raeesah says: “If I leave him to run with other children, he will sit and he'll watch them and he won’t make an attempt to go. Like I said, I have got to go and push and encourage him. So I don’t have time to sit with the moms and talk. It is what it is. I've got to take him. So if you look at my at my social battery, 10% is just eating with the moms and 90% is taking him out”. She is here and she is there (Paradox 5), transcending the role between being *with* mothers and *being* a mother.

Something that resonated strongly throughout Raeesah’s interview was her acknowledgment of community. They have always been surrounded by community yet they are not exactly a part of it (Paradox 6). It is incredibly nuanced. Yusuf is known and loved and maybe even a bit of a celebrity at places they visit frequently; he charms the waitresses and captivates the baristas and gets an extra tasting at any ice cream parlour.

“I have no issues with community. Everywhere in the malls, public places, like restaurants. They’re all brilliant, everybody talks to him and everybody loves him. He's like, like you said before he's a celebrity. Everybody wants to know him. He likes people and people do love him.” A bold and confident statement from a mother who always seemed a little bit unsure. She knows with certainty that he is loved. But did that mean he was included? These scenarios Raeesah mentioned always have her at his side. She rarely ever leaves him. It has echoed loudly every day since her interview: “…so people take him if I need to be out and whatever. They are always ready to take him, to be with him. But he can’t communicate with them. So I have to be with Yusuf all the time.”

She has to be with Yusuf all the time.

Of the future, she seems certain of one thing, that Yusuf will always need somebody by his side: “So basically as I’m sitting here right now, I know that in the future I need a helper for Yusuf. So if I’m not here one day, I need somebody to be able to take Yusuf to the store and get him what he needs. I know that as the world is right now he can’t live on his own. We need somebody to guard him.” To guard him. She speaks so openly of a community who loves him but at the same time she needs to make sure he has protection to be out in it (Paradox 7).

Her life has been full of pendulums like this. She has received amazing support from her family but at the same time they don't understand (Paradox 8). They are there for her and gather around her; they raise her up but then they question her parenting and they let slip their dreams for Yusuf that have wounded her even though that is not the intention.

With her head down, she admits "Also with his granny, she really wants him to talk. Six years, he hasn't said anything. Like, I need people to understand that there are other ways that he can communicate. Other than words, I don't know why he can't talk. He knows what he wants. It's just the brain isn't synchronised with his mouth. Probably. But that is where we're at. If you can use pictures rather than words, fine by me." This is a key consideration. For Raeesah, having alternative communication is just fine, as long as he can communicate.

But the burden still falls on her to champion this. After six years, the expectation is still on speech and it is hard for her to reconcile when she understands every vocalisation and every gesture. She is supported but "I don't let anybody do things for him. Because I feel I know best". (Paradox 9). She knows sometimes progress can be slow but that it can happen. She recognises his differences and acknowledges them daily. At the very core of her hopes and dreams for Yusuf, is for him to just be included. He is an observer and often needs her help to begin an interaction with other children.

Raeesah would love children to understand when others are different and to be able to slow down to include them. She would love for a child to stop and take the time to bring him along — at a park, on the playground. She just wants him to be happy and she wants him to be independent. To live a life where he is able to do things on his own, go places on his own, make friends, maybe even have a job. She wants a full life for her oldest child.

They leave together, mother and son. She follows him and adjusts her orbit ever so slightly to this, the centre of her universe. As he reaches for her hand, hers is already waiting. She knows before he does, as she always has done.

Story 4: Introducing Ncebs

One of the most powerful stories I have heard and would love to share with you is that of Ncebsi and the light of her life, her daughter, Aliza. This interview sat with me every day. It has coloured the way I interact with people I meet; it has taught me to be aware of my own judgements and biases and has only strengthened my determination to keep going. These types of stories fuel my professional growth.

As a speech therapist, this story is not something I would have learnt from a case history or parent interview and yet these are real problems that Ncebsi and Aliza face daily. As the story unfolded, I was humbled by their tenacity and ability to adapt to a world that was not created for them. Part of our responsibility as therapists is to help young children access their environment. Communication is my main priority and it is universal; it requires multiple communication partners in multiple environments and yet that is not my focus. For occupational therapists, the focus is on activities of daily living and the activities that help individuals live their lives, be that taking public transport, grocery shopping, or navigating your home. These are challenges Aliza continues to face because that is not the focus. Tasks that involve others, that require others to be willing to include them should be where therapists are looking. Why isn't inclusion at the forefront of everything we do? I believe stories like this hold immense power to move people to change. It did for me.

Ncebsi, or Ncebs as I also call her, is a petite woman. She holds herself like royalty, laser focused, chin high. She is gentle, kind and respectful. She is a quiet presence who never takes up too much room. She is humble, filled with a youthful exuberance, and wise beyond her years. But do not be fooled by her beaming smile and bright eyes. Ncebs can be fierce. She has had to be because all her life she has had to fight. She was born and raised in Bizana, a small town in the Eastern Cape province of South Africa. It is known for raising fighters — anti-apartheid activists Winnie Madikizela Mandela and Oliver Tambo were both born there.

She has overcome much in a short life. She has had to learn to embrace the spirit of Bizana and fight for herself, her family, her daughter, and her life. Ncebs is fueled by Aliza. Every decision she makes, every step she takes, every challenge she overcomes, are all for Aliza. When she was quite young, she lost her mum and never knew her father.

She was raised by her mother's family. All along, she was their hope freshly out of matric, on her way to education and employment to make the family's dream for a better life come true; until the pregnancy. It was a shock and the first step in a long and tumultuous journey for Ncebs who knew very early on that she would do anything for Aliza. Ncebs first fight was to keep Aliza but not her last to protect her.

Ncebsi's Narrative: Fight or Flight?

Fight or flight are the most basic of instincts. Gut reactions that save us from harm. A primal response; unthinking, unreasoning, always protecting. Just like the love a mother has for her daughter. This is how Ncebsi has navigated life with Aliza, in flight or fight depending on what the situation demanded. She is always stalked by the unknown and living in survival mode. She relies on her adrenaline to get her through most situations, her careful assessment of her environment, and the people in it. Coiled like a spring, waiting to soar into fight or flight; a mother lioness, ready to pounce; a volcano bubbling under the surface. She is always dressed in armour because she has to be.

Ncebsi is a single mother to Aliza, who was born deaf, blind and developmentally delayed in a small rural community in the Eastern Cape. Ncebsi was told in no uncertain terms that Aliza was cursed by ancestors, punished by her mother who had long passed away for bringing shame to her family by becoming pregnant as an unwed child. Aliza needed healing, fixing — miracles that cost money. Despite all the whisperings and judgment, Ncebsi is a humble woman, with a quiet strength, who has fiercely battled to get someone (anyone) to listen when her intuition could feel something was not right. On a daily basis, she fights for Aliza and, on top of being her caregiver, she is also her greatest ally, supporter and bridge to the world around her. She has found community with strangers in taxis and kindness from people in the streets, but in the end, it is always the two of them against the world.

From the time Ncebs entered the medical system she was constantly dismissed. She had to be on guard and prepared to fight. On the day Aliza was born, the doctors denied that Ncebs was ready to give birth, and yet she did that same day. When she first held Aliza, she noticed something unusual with her eyes and again, the doctors dismissed her concern. It was Ncebs' unconditional love and constant determination that kept her going. She went back again and again to fight against a system that belittled her, minimised her concern, tried to take her power. Her first choice: fight or flight? Here she chose Fight.

Finally, when doctors admitted that there was a problem, Ncebsi was faced with further challenges within the health care system (she chose to fight). Overcrowding of hospitals and staff shortages meant that Ncebsi had to make the long trip to the hospital multiple times for Aliza to get the help she needed (another fight). She was told by medical professionals that "Aliza is too small" or "there are no beds". And yet, she persisted. When the local hospital proved ineffective, she found another way.

She travelled to see a specialist in East London only to be told that she needed a referral and transfer paperwork from the current hospital to access the service (more fighting). She was also a walk-in, so she was sent away. But she went back to fight yet again. To be heard and seen. Sometimes the bureaucracy felt impossible. Aliza eventually got the surgery she needed to help relieve the pressure in her eyes and Ncebsi was finally taken seriously, but at the cost of time for herself and for Aliza.

Ncebs' search for answers didn't stop there as she explored every possible avenue. She was told it was the work of witchcraft, curses and ancestors when she visited sangomas and healers to get answers (fight, fight, fight). She visited Aliza's father's family for closure, for guidance, perhaps even for hope. Instead she found cold shoulders and misery.

The ancestors were divided she was told. "The Angry Ones" cared nothing and refused to come to her aid but "The Cool Ones" thought that Ncebsi should receive this blessing of a child albeit with a disability. She was told over and over again that Aliza was her punishment for bringing dishonour to the family by having a child out of wedlock. The solution was a series of expensive ceremonies, none of which Ncebs could afford, the alternative of not doing them was death for her daughter. An impossible situation for a woman just trying to find her way (another fight).

She went to her mother's grave and asked her why she would want this for her. It was a period of great pain walking this road alone, but she put that pain away, allowed it to fade to background noise because Aliza was the most important thing to her (fight). Through sheer force of will and powered by a hunger for answers, Ncebsi found other specialists who could help Aliza and it was this investigation that led to her to the province of Kwa-Zulu Natal. She was embroiled in a battle against the medical and the supernatural (fight).

At this time, Ncebsi's family encouraged her to leave Aliza behind so she could get a job. But for Ncebs, she had seen too many children like Aliza forgotten and hidden. She made the decision to move to Durban, just the two of them, against the world (this time choosing flight). This both did and did not make all the difference. In her search for community, Ncebsi visited a few churches and was asked for money in exchange for a miracle — pastors offered healing in exchange for payment. She railed against her core beliefs as she questioned deities that required financial incentive to help their loyal and dedicated disciples (another fight). And still, Ncebs did not break.

Ncebsi has a strength into which she has funnelled all her fear and all her doubts. The journey to Durban was formidable and marked with unsanctioned bovine crossings, potholes and uncertainty. She left all that she had known to make it up the proverbial and literal Wild Coast to reach a new city she had never been to for a service she hoped would be what they needed (flight for the fight). She was powered by Google. Ncebsi threw herself into research — for the best doctors, the most answers, the people that could help Aliza; for anyone who would listen. Through pure determination and grit, and running miles and miles around bureaucratic red tape that tried to trip her up at every turn, she found hope. Ncebisi and Aliza now live in a sprawling informal settlement in Durban. Ramshackle dwellings are scattered across the hill, packed onto earth, made of tin and wood and any spare parts. Held together by wishes and prayers. It is expansive and, from the ground, it seems like innocuous residences cobbled together, filled with people making their way in the world.

But in this settlement are secrets of struggle, violence, impermanence, and hope — a hive of entrepreneurial spirits, hard workers and dreamers. And hordes of disappointment, unrest and injustice. You will find people rising with the sun, heading off to their jobs, crammed into precariously filled taxis trying to make a better life for themselves. This was their home now. Their fresh start. Where Ncebs finds hope, she also finds hushed voices, not so hushed judgements, stares and finds unkindness.

Public places were often a challenge. Many times, Ncebs heard children in her neighbourhood refer to Aliza as a monster because of the way she looked, the way she moved, the sounds she made. Aliza's milky eyes, vocalisations and repetitive rocking instantly marked her as different. Ncebsi would, many times, go on to hear the name "monster" from adults and other children too. It was like Aliza's condition was dangerous, contagious. An affliction that was meant to harm and damage. But Aliza was just a baby.

One day, while out at the shops Ncebs and Aliza were followed by a little girl who did not want to know but just wanted to stare. Aliza was a spectacle, and this meant that often the two of them were shunned in places they should have been welcomed. On this particular day they were followed by this little girl like a spectre. Ncebsi offered her the choice to meet Aliza. She declined but continued to follow. Ncebsi offered to help her find her mother. She declined but continued to follow. Eventually she disappeared altogether.

When they next encountered each other in the queue to pay, the little girl was in tears, telling her mother about how afraid she was of Aliza.
The mother, then became upset and complained loudly. “Why is she making so much noise? She’s scaring my daughter. This child is making my child uncomfortable. We’ve got rights as customers. We can’t just be here and be made to feel uncomfortable. I’m going to leave my basket here”. There was Ncebs with her sweet toddler in her arms and a basket full of groceries who had the patrons turn on them with what felt like pitchforks and fire. The manager calmed the mother but did nothing for the two of them. The situation was becoming heated and here it was again, the fight or flight. This time she chose flight.

The stares were unmistakable and still no one came to her aid, so she did what she has always done and made the best decision for Aliza in that moment. Ncebsi eventually left her unpurchased necessities and fled the store so as to not escalate the situation. It ruined that day and it haunts her still. It was not the first and it was not the last. On the one hand, Ncebsi is determined to not hide Aliza away. But on the other, her mind is always on an escape route, planning the eventuality when she needs to find a new supermarket, a new shopping mall because they were not welcome. This is the life she leads in fight or flight.

As bleak as these mundane interactions were for them, all hope was not lost. For Ncebs, it was the strangers around her that became her community. Strangers at a taxi rank who offered to help carry her load, or passers-by who offered a kind word. In 2022 when disastrous flooding hit Durban, Ncebs’ dwelling was in grave danger of quite literally slipping away in an imminent landslide.

It was not safe for her and Aliza to be there but they had nowhere else to go. On a taxi on the way to buying nappies with no clue as to where she was going to sleep that night, she met a woman who took her in, gave her shelter, offered up clothing. This woman didn’t know them at all but she was moved by these two and the depth of their connection. She didn’t have to do anything but she offered a lifeline until Ncebs could get back on her feet. It was through these unknown faces that Ncebs found her way. It was *ubuntu* that moved her forward.

Of Aliza's future, Ncebsi says "I'm just saying things are going fine. I'm not thinking 'I wish my child could be like this', because now I have accepted that she's got these disabilities. Now I'm just looking for what can help this. What is the way forward to help her to do this, to do that…What's the next step to take?".

There were a few professionals (an occupational therapist in particular) and educational institutions who gave Ncebs the support she needed to keep going. When asked about where Ncebs felt the two of them were included, where she felt Aliza would be loved, where she felt like she could exhale, she highlighted Khanyisa Developmental Centre and Bright Eyes Centre. For her, it was that people at these institutions were kind, curious and dedicated to help her finding some answers.

For a pair who is always on the go, we touched on the feeling of "home", a place of safety for most but this is not your typical story and so this was not a typical answer. Aliza is always on the move, for a child with no sight and no hearing she understands her world through movement. For Ncebs this means she is always hypervigilant, always following. She is assessing every situation, danger, risk to be one step ahead of it. Even somewhat menial tasks like cooking are fraught with peril if she turns her back. She is always "on" — on guard and on edge. She is ready for the fight or the flight.

The hope in Aliza's story lies squarely on the shoulders of Ncebsi. It is her drive, determination and willingness to do anything for her daughter that keeps them going. They are still on the search for their community. They have found salvation and sanctuary in pockets along the way that seemed to come at just the right time for Ncebsi to be able to jump the next hurdle. There is no rhyme or reason as to when and how she is supported. She just keeps taking the next step, educating the next person, moving on when she needs to, and hoping for the best.

5.1. Analysis of Narratives: Level 2

Being the keeper of these narratives is a position that one feels privileged to hold. Each one was so vastly different but each one had vital messages to share. There were key themes that emerged that have become the pillars of this study. They have been humbling to explore but exactly the kind of intricate motifs that have woven themselves into my practice and that have marked me so deeply.

5.1.1. The Fight for Inclusion

Though each family comes from different walks of life, they all highlighted the battle it was to find their place in the world. For the Rogers it was the staring that always made them feel unwelcome; for the DaCanhas it was the fear of judgement and rejection that held them back from searching for belonging. For Raeesah it is a burden she carries on her own, and for Ncebs, it is still a daily struggle. It is not an uncommon fight, this fight for belonging, that families who have children with disabilities need to steel themselves for (Antonsich, 2010a; Mitra, 2018; Scior, 2011). Whether it was learning how to deal with stares from strangers or cope with well-meaning familial advice or going up against a behemoth of a medical system where their concerns were constantly dismissed (Lalvani & Polvere, 2013; Reindal, 2010). Inclusion was not found, it was created.

Each family had their own journey to find belonging, acceptance and a place they could exhale but they all had to carve that path in a way that most neurotypical families wouldn't have to through fighting, defending and searching. It was their bravery to keep returning to places where they were showed kindness, like the ice cream parlours Raeesah and Yusuf frequented, and it was their wisdom to avoid places where they were greeted with disdain, like the store Ncebsi and Aliza fled from. The Rogers spent years roaming the wilderness of the world and though they reached out for help from organisations that were supposed to support them, they had to find their own way. Acceptance was not something freely given. There is so much thought and adrenaline in frequenting places most neurotypical people visit on a daily basis. Ncebsi, Sarah and Debbie all mentioned experiences they've had at the supermarket and each of them has had a different outcome. Going into the situation there was so much fear and only Sarah walked away with a sigh of relief.

On a different occasion, Sarah recounted a story of Ollie enacting his favourite scene from *How to Train your Dragon* in the middle of a supermarket once. It was being part of a Viking horde, wielding a pretend axe and letting loose an impassioned battle cry. It terrified a little girl standing nearby and when Sarah tried to explain the situation, the mother wanted none of it. Even for Sarah, who had found this experience of going to the supermarket soothed by the understanding of others, it was still not always a happy ending.

Both Raeesah and the DaCanhas mentioned how hard their families tried to understand, how they offered support in so many different ways: research, pick-ups and drop offs, stints of babysitting. It was so well meaning but still isolating because no one truly understood what it meant to have a child with a disability. The hitting was not naughty, the screaming was not unruly. It was communication and they were trying.

The search for inclusion can be isolating and heart breaking. There is often frequent rejection before there is acceptance, if acceptance comes at all (Halder, 2017; Kaley et al., 2021; Robinson, Fisher, et al., 2020). Each family has some sort of description of walls or armour in their narrative and it is because each of them have had to be prepared for a fight every day. The societal norms we have created that allow us to be a part of something bigger can also be a barrier if you are not cut from the same cloth (Singh, 2023).

5.1.2. The Burden of Communication they Carry

As a speech language therapist, communication is my focus. For each of these families, communication was my focus. For years we had worked together but it was only after undertaking this project that I stopped long enough to really hear their stories. Each child in this story experienced challenges when it came to traditional communication. They weren't necessarily effective through speech but there were other ways of getting their messages across that needed enhancing. For Ollie and the Rogers I had recommended Makaton; for Raeesah and Yusuf it was a core board; for Tate and his parents it was Makaton and visuals; and for Ncebs and Aliza it was tactile visuals and gesture.

There was an additional thorn in my side that I noticed during Raeesah's interview. She said: "I didn't know about the communication board. When he was younger, the [speech] therapist told me about the communication board but it didn't make sense to me at the time. It looked like pictures but Yusuf does not understand what this picture means. Like for the stop sign, Yusuf isn't gonna [sic] understand. Actually she just gave, she just emailed that to me and told me to teach that to him. So that didn't make sense." She summed up the burden so simply, so powerfully.

The grand finale of AAC intervention is the hand off, the home implementation that parents are burdened with, the "you do it". But when the parent is not ready to take up that mantle, who gets to decide? Is it the therapist who has spent 20 sessions modelling in their therapy room or is it the parent who could not possibly take on any more than they already had? It is historically the therapist who gets to have the final say: an emailed communication board and the wish of the best.

These enhancements of communication were something new on top of something that was already so unknown. Each family has highlighted how murky the future looks and how much they have had to embrace the unknown. So much capacity is spent on not knowing and figuring it out, and then therapists come in with something new and unknown and add to the pile. For this mum who had to unpack what this diagnosis meant for her only son, here was just one more thing she needed to figure out.

Something that came through in the DaCanha's interview was how hard it was when Tate was non-speaking. Debs said: "it was just difficult he wouldn't speak, he was non-verbal. And communication was hard. And dealing with two young kids was hard, trying to show [his sister] love and attention when your brother screaming at night." We worked hard on setting up each of these systems and then we worked hard on each family using them and then we worked hard on getting them into the classrooms and then my work stopped.

I wasn't there for the nights Tate screamed, for Ncebsi's judgement at the supermarket or Ollie's Makaton not being loud enough at a birthday party. I was not there to see the failures of the communication systems but I was there at school to remind them of just one more thing that needed to be done. And in that space, each one of these families had to find the strength and the courage to carry these communication gifts I had given them and share them with their communities (K. L. Anderson et al., 2015; Bondy, 2019; Trembath et al., 2022; Wickenden, 2011).

It was a massive realisation that my hard work stopped too soon. Raeesah summed it beautifully when she said "Also with his granny, she really wants him to talk. Six years, he hasn't said anything. Like, I need people to understand that there are other ways that he can communicate." Communication is a gift but only when it is shared and so much of my work happened in a vacuum (Staley et al., 2022). I had waved to his granny many times in the parking lot as we welcomed Yusuf to school every moment but I had no clue this burden was on Raeesah. She was so accepting of Yusuf's communication but she was fighting the battle of acceptance all on her own.

The community members were able to talk about inclusion and belonging and share their viewpoints on what made it so when it came to disability but there was little said about communication. My understanding of this was that where Tate and Ollie had some words and needed a little deciphering and decoding, Aliza and Yusuf did not. Ncebsi and Raeesah were the parents who had to rely on themselves or the kindness of strangers because communication was so subtle, so nuanced, it fell to them to be translators. The community was able to make accommodations for speech but they did not know how to do this when communication was anything other. How telling that Ncebsi and Raeesah had the most difficulty in identifying communities where they felt included.

Though the community interviewees overall were so accepting of disability and inclusivity in a broad sense, communication was not explicitly one of those things. For Ollie to say "Peezo" and have it understood as "Freezo" was more about being willing enough to decipher his speech. It would have been interesting to know what communication support looked like from a community perspective for our non-speaking families. To those who know Aliza, there is always a comforting rub of the arm for her to know that someone new is there. This is followed up by a moment of stillness where Aliza is allowed to breathe in your scent to understand that you are not her mother, you are someone else. It is an intimate gesture and takes much more time than a "hello" or "goodbye". I have not known anyone to greet her who is not already working in the field of disability support and will make the effort. For Yusuf, there is always a high five waiting. I have seen people charmed by him tentatively offer a high five in a greeting.

Over the years, I have come to notice that the tentativeness comes from not knowing. The well-meaning gesture of even a simple high five is tinged with fear, rejection (being left hanging as they call it) and not knowing what to expect. Sometimes when Ollie is maxed out on being around others, or suffering from a lack of sleep, he does not want to talk or sing with you. Sarah is always there with an apology: "I still find myself jumping in to either apologise for his 'bad' behaviour when he's having a bad day, whereas with Calla (his sister), I would never."

This is not to say that any one of these journeys have been any less significant but it is illuminating that even under the umbrella of disability there is a hierarchy of communicative power and alternative communication sits at the bottom.

Surely it is our professional responsibility to make sure alternative communication is understood by all? And yet I had no role in ensuring Ollie could ask for help in Makaton and be understood at his supermarket, or that Yusuf's "stop" was universally understood by any child at the parks he frequented. For families that already have so much to carry, it was just one more thing to shoulder.

5.1.3. The Flaw in the System (and the need for change)

The more I listened, the more I realised our system was flawed, our practice was limited and our reach wasn't nearly as far as it should be. Communication happens all day, every day. It is interacting with multiple people, some known and many unknown and is woven into everything we do. It is one of our most basic forms of human connection (Beecham, 2005; Rose et al., 2016). Hearing Raeesah mention that she needed to be on the playground with Yusuf, and Sarah retell how she had to defend Ollie at the restaurant. Hearing Debbie and Jono talk about how they felt like they were drowning at home, and Ncebs explain how she always needs to be "on" for Aliza. It is moments like that these that help me understand where the profession is failing.

When talking about Yusuf's communication in our interview Raeesah spoke about Yusuf and his behaviours saying that they do not make him naughty, but are necessary to make himself heard. She said sometimes he hits you if you're not listening but it's his way of saying "I don't want to eat that apple forced down my throat, I'm going to hit you". For other families it is naughty and wasteful, but for Yusuf he is just trying to tell you he doesn't want it.

I tried to affirm her by saying: "Every behaviour is a communication right? Your child is laughing, crying, hitting everything is communication and it all means something. And again, as a parent or someone like Yusuf, you are the dictionary. You know hitting and what that means; when he takes you, you know what that means; when he makes a noise, you know what that means". She immediately perked up and responded with: "That's where your research comes in handy, is where the community needs to learn what that means." Raeesah said of her experience with speech therapy for Yusuf: "Some people [therapists] have done really well theoretically but when it comes to putting it into action they don't know how unfortunately. So they need to be taught empathy and all of those things." The fact that Raeesah thought professionals needed to be taught empathy, and that it was not something inherent in every therapist, was a sobering reality. If that doesn't indicate a need for some kind of change, I'm not sure what does.

Ncebsi spoke about the journey of unpacking Aliza's disability. She told me the circumstances around her discovery that Aliza was going to carry this disability with her throughout her life. She said: "We…as black people, we believe in ancestors. So, in my family, I first went to a sangoma [when I found out Aliza had a disability]. He told me that my mom, my late mom is not happy that I'm pregnant. He said the ancestors are on her [Aliza's] shoulders. They're fighting with her. So that's why Aliza was born [this way], so my mother punished me through Aliza. And then I was like, how cruel is that? You know what, I'm just going to go to the grave and ask mum, how can you do such a thing? To me? And then the sangoma said, 'No, you have to do a ceremony' and apologise to her for what we have done. And then I did, but I had in my mind — how could she do that? If she is really my mother, how could she do something bad like that? And then after I've done those things, things just got worse. And I decided okay, let me stop. Let me just focus on getting [her help] because even the hospitals, they'll just get irritated when we get there.".

Her story wrenches my heart deeply even now and though we are supposed to be clinicians first it is impossible not to be affected by this story. There was such cruelty, to use her words. She has been carrying a massive burden.

On the one hand, I know the rate of burnout is high within the profession, there is care and effort made and there are always those who go above and beyond. But at the same time, putting up professional boundaries that prevent us from hearing these kinds of stories is doing a profound disservice to the families we serve and limit our understanding of what they need.

Additionally, this cultural perspective was new to me. It was a shattering insight into their lives and how Ncebs is not only fighting against the physicality of Aliza's disability, but also what that means for her mentally, emotionally and spiritually. It is a fight against her ancestors, the very foundation of who she is. There is warring information. There is a woman who knows that healthcare professionals will be *irritated* when she asks for help. It has filled me with the deepest shame. What case history question could lead us here? None I could think of. Because we focus on the diagnosis, on the deficit, and the plan going forward.

And yet here is this mum, so willing to share her story and journey because Aliza is not just disabled. She is locked in a battle with the ancestors. She's a blessing and a curse. Is she suffering because of Ncebsi's decision? How on earth do you shoulder all of that and still get turned away because you cannot afford the help you need or are faced with disdain from the institutions that provide it? It has been heavy for Ncebsi to carry this all. And where do healthcare professionals fit in? It would seem nowhere.

We are not born to save the world and this is not what I am implying. There is so much systemically wrong with what Ncebs has experienced, but we can offer kindness and reflection in a system that has been so cold. We can open up a space for parents to share the load, to offer safety and share. We can be the person that listens. We are not psychologists, but we are professional communication partners and communication encompasses all of those things: sharing, listening, holding space. We talk about holistic care, the International Classification of Functioning, Disability and Health, the impact of environment and participation, so how can we not take into account the impact of this journey?

Individuals with communication impairments are perhaps one of the most underserved communities (Harsha Kathard & Pillay, 2013). And yet, why does so much of our practice happen behind closed doors or at such a high cost? Our current practice model leaves communication at the front steps, out in the cold. Just like a lot of the families here who could not afford to access to private speech therapy (Barrett & Marshall, 2013; Pillay et al., 2020; Watermeyer & Barratt, 2013).

In South Africa's vast landscape of socioeconomic turmoil, SLT services are gatekept by politics and years of injustice (Abrahams et al., 2022; Harsha Kathard & Pillay, 2013). The practice model needs to change in order to provide accessible and equitable service (Pillay & Kathard, 2018; Staley et al., 2022; Wylie et al., 2013).

These families are among the minority who could access SLP services with great financial sacrifice. Raeesah, having been down the road of trying to access service when Yusuf was younger, said "you have to have money in order to get him to where you need him to be. There's nothing that the R1 800 that the government gives[7] you is going to help. So we need more free service. Free service to help them every day. They need therapy — it's not just once a week, that isn't going to help. Or even if you do need to do it once a week then the parents need to be shown how to help [for the rest of the time]. But you have to have money. Therapies are expensive." For this child, where access to communication would unlock everything, we are putting a price tag on basic human rights.

[7] This is a monthly payment from the South African government known as a Care Dependency Grant if you are the parent, guardian, foster parent, or custodian of a child under the age of 18 who requires full-time care due to a mental or physical disability.

5.1.4. Reimaging Communication in the context of Community

Everyone has their own definition of community which is evident in the narratives above. For some, community is family. For others, community is a space. For some, like Ncebsi and Raeesah, community was difficult to identify. And for others still, community was the quiet moments of *ubuntu* where strangers reached out a helping hand. Broadening the idea of what makes up community would help us understand how to engage as a profession (Berenguer et al., 2022; Wickenden, 2013). Community is the interaction between institutions and people and not something static that applies to everyone. Community is a very personal construct and unique to each family (Miolo & DeVore, 2016). Stories are therefore vital for understanding community (Brunton et al., 2017; Verdon et al., 2016).

What really came through in every narrative was the web of communication that each family interacted with — sometimes it was with business owners, sometimes it was with shop assistants, managers or waitresses. It was people they knew and didn't know. It was those who had the patience and desire to stop and listen and others who looked to the parents to decode for the sake of efficiency. It was an adult asking a well-intentioned question, it was a curious child. It was a cry for help on a busy playground, and quietly admitting fear of the dark. That web reached as far as grieving over the loss of a grandparent and sharing a love of thunderstorms. Communication was widespread across these people, contexts and subjects for all these families. It was no modelling "want" or "more" or "go" in a structured and finite therapy session. But regardless of the context, the responsibility of alternative communication in every scenario was on the shoulders of the families (Berenguer et al., 2022; Light & McNaughton, 2012; Mandak & Light, 2018).

Sarah shared: "I was having a discussion with two moms this morning. They were asking me: how can we stop our children from being cruel to him? So I love that. I was so receptive and my response was 'Children are only cruel when they come from a background where parents don't show acceptance to diversity whatever that looks like.'". An excellent point! Inclusion starts with community and that can ripple through generations. There is systemic work to be done and the disruption that causes the ripple needs to be made now.

There were so many opportunities for education and intervention upon reflection but that is not where the current focus of SLP practice lies (K. L. Anderson et al., 2015; Blackstone et al., 2007). Communication intervention could benefit from a community lens to support alternative communication and to promote inclusion and belonging in most environments (Abrahams, 2019; Donaldson et al., 2023; Friedman & McNamara, 2018; Staley et al., 2022; Wylie et al., 2017).

5.1.5. A moment for Inequality

Of these families, all were middle class except Ncebsi. There were two white families and two families of colour. Though every one of them was failed by the medical system, none more so than Ncebsi. I mentioned earlier that black females were at the bottom of the hierarchical order of life and this was stark in her interview. On top of trying to manage Aliza's disability, she had so much more going on.

She said: "It's gonna [sic] be hard for her, I need to be strong myself. Just for the sake of her, because she doesn't have anyone except me. I just had those thoughts, that okay. Now she's deaf and blind, and I'm the only one she's left because her dad is not in the picture. So now if maybe I have to stress myself and not find help, where she's going to get help? So I must be the one who's going to be strong enough to get help and talk to people and get some ideas."

Ncebs is 24 years old and this is what she carries on her shoulders. She is not just the sole caregiver, she is also the sole researcher, navigator, and provider. She has been through so much. She has felt broken. But failing was not an option. Slowing down, giving up, being anything other than determined were not options.

When Aliza started at school she said: "When I'm here it's like we were on holiday. I even remember that break that I took. Five minutes because I'm with her full time so that's where I got to find myself." She got to find herself at [Aliza's] school because it is one of the only places she gets a break. There is no family support, there is no friendship, there is only Aliza. It is a humbling thought to consider for how much of her time Ncebsi is the person. Aliza is only at school a few hours a day and that's the only time Ncebsi gets to take a break.

I once saw her frantically tapping on her phone at the back of the classroom during snack time and when she re-joined the group she calmly remarked that she was trying to submit an assignment for her classes she's taking because she only really gets to work when Aliza is asleep or at school. She uses this down time to find a moment of peace, while also using it to better herself. She always has one eye on the present and one on the future, and I can't imagine the weight of needing to traverse these two every single day.

She is constantly in a state of fight or flight and heightened adrenaline. I wonder what effect this has on her body and mind. "You see our environment is not a good environment for us, but we just don't have a choice because we are close to Aliza's services. It's where I can easily reach her hospitals. It's even easy to come to school. There is no peace where I stay there. There's a lot of violence". It's not a good environment for them but it is a place where they need to be for convenience.

Ncebsi has struggled with finding service that was impactful, like the others have struggled, but she has also had the additional burden of needing to uproot her entire life to move closer to the services that Aliza needed. It is so unfair and unjust. It is so cruel. But it is a reality we have come to accept and I know that theirs is not the only story like this. Of her journey thus far she said she relies on a wish and a prayer, and winging it every day. She fights for stability but that is not something they can achieve right now: "If I get the help, thank you God. If not, then I just beg. Keep sharing my story to people. Like that's how I ended up finding my own way of living without listening to someone else. If this child needs that then the child needs that. I just stopped everything and focused on her. As long as we have food today. Then we'll see tomorrow what we're doing. I was financially broken, emotionally, physically."

So much to unpack here. Firstly, the bare necessities were something that were hard to come by. Food was something she could only consider day by day. Once she was fed today, she had to start the journey all over again tomorrow — the search to feed her child. Secondly, she was broken (in her own words) financially, emotionally and physically, and she kept going. She had to keep going for Aliza. She showed up for every therapy, at every hospital appointment, and I wish I would have thought then to ask if anyone had asked how she was doing. Or even more whether anyone had time to truly listen to her answer. Through sheer luck Ncebs found professional networks with hearts for helping, not just for the job, and in little ways they moved her along. It was a jungle out here and Ncebs was all on her own.

It is a stark realisation that there are so many parallels in these stories and things have been hard for everyone, but things are so much harder for Ncebs. From the very beginning of her life, Ncebs has had to start on the back foot. Her fight has constantly been without weaponry, she has not been armed financially, emotionally, spiritually, or socially. She has always had to do this alone when the world around her has been so harsh. Apartheid ended 30 years ago, but how much has truly changed?

And then the point that stuck with me most of all: sharing her story was a way for Ncebs to reclaim her independence. Her story was a map for her to find her way in the world. On days when she had nothing, she had her story. Stories for the most part through this PhD have felt idyllic and naïve and simple but here is the raw honesty. Her story speaks truth to power and while she may not have everything, she has this. They all do.

For every time these families have felt silenced at a hospital, or judged in public, or hurt, disappointed, or exhausted, these narratives are theirs. They are always in control of that and what a gift it is through the turmoil and heartbreak of having to shoulder so much.

Chapter 6 - Workshop Analysis

This workshop was a culmination of months of interviewing, honing in on the research question and carefully curating the stories in a way that would make the most impact. It was walking these stories out into the light. This would be a key moment in the research process. These stories were the most vital driving force behind my research and the reason I undertook it in the first place. I found the sharing of them moving and somewhat sacred for me within the profession. It was time to find out if they meant the same for others as well. I felt privileged to be able unleash the power of these families and the professionals who work alongside them.

6.1. The Pilot Workshop Learning

Below, in Figure ,7 is the visual representation of the main themes explored in the session. A lot of learning took place thinking outside the box and breaking boundaries. The process of unlearning is represented here by the hammer shattering the known. The need for innovation when thinking about inclusion came up often but probably asked more questions than it answered. It was exercise for the brain. It is represented here by the brain emerging from the box with questions and complex thinking (the gears). The chain unlinking ties to the books of rethinking, relearning and challenging the knowledge obtained while learning to become a professional. The workshop was a lot of undoing. The structures represent the institutions that the participants felt had let them down.

There was many a mention from the professionals of feeling unprepared when leaving university. The birds symbolised breaking free, and letting go of what was known in favour of the unknown, for the sake of creating a more accessible and meaningful practice. The following process of shifting practice was not clear cut, therefore the pendulum was used to symbolise it. There were fluctuating opinions as to who was responsible for community education, equipping parents and communities, sharing the load as therapists, but there was no final answer.

Two things were clear: first was the need to shift the nature of the power dynamics as represented in the valley and the cliff; and the second was the community aspect, the need for togetherness and recognising that every person in a child's life could be a puzzle piece that made up the full picture. It emphasised that everybody had their own knowledge to bring to the table that was different, not less than. The people at the bottom symbolised the need for community to create a sense of belonging and bring *ubuntu* to life. The leaves and grass symbolised the growth that each participant experienced during the course of the workshop. The themes will be discussed in more detail below.

Figure 7

Graphic Harvesting representing the themes of the workshop

6.2. The Final Workshop

As the culmination of months of emotional and professional investment drew near, nervous energy was in no short supply the morning of the final workshop. In attendance were myself, Rizwana (co-supervisor and graphic harvester), Seyi Amosun (an observer representing the supervisor) and Sarah Rogers (as co-facilitator and parent participant). The participants were from a variety of backgrounds: racially, culturally and professionally. We had new and experienced teachers, psychologists and SLTs in attendance. There was one participant (an audiologist) who was unable to make it on the day due to illness.

The workshop was once again held at Khanyisa Developmental Centre. P.M. is a psychologist who has practised internationally and in South Africa for the past 5 years. T.G. and R.B. are teachers with three years and a year of teaching experience respectively. L.N. is an SLT with two-and-a-half years of experience.

As with the pilot, Ncebsi's story was the one that generated the most robust discussion. However, having Sarah present as co-facilitator and parent added another layer of discussion and first-hand experience. She was an invaluable resource to the workshop and all the attendees. Our stories have been intertwined since 2016 and the insight she shared with me over these last few years have been instrumental to my learning. The relationship I built with her and Ollie over the last eight years has been vital to my own evolution. She was my double agent, the attender of all therapies but also a mum who had an incredibly busy life. Without knowing their story, I never would have found an "in" with Ollie through music. Without being at Ollie's fourth birthday party, I never would have seen how Ollie's communication impacted his life outside of the classroom. Without seeing him with his grandparents at pick up time, I would not have known how difficult his Makaton was to grasp. Their story was the greatest and most meaningful guiding star.

Sarah taught me to listen to a parent's expertise and her dream for Ollie, coupled with her strong will and fierce determination, taught me how to really become a part of co-creating in a therapy space. I was grateful to have her be part of my project in such meaningful ways and to have her by my side on this day.

Workshop packs were given to participants beforehand so they could immerse themselves in the story. There were also a few quotes that were added about what it means to parent a child with a disability that I had Sarah approve and elaborate upon that in the second half of the workshop. The visual that Rizwana created was beautifully and artfully representative of our discussion. The words in the visual were the concepts that came up throughout the workshop. They were all linked in such a way that we looped back to them; went round and round with them. In the middle in the brightest and most vibrant gold is written "Live Loudly" — perhaps one of my favourite concepts to come out of the workshop. There were many themes that mirrored the pilot workshop but that had rich perspective given the variety of backgrounds of the participants.

6.3. Workshop Analysis

Stories hold deep and meaningful power and are most impactful when shared.

The pilot workshop was key for setting up learning for the main workshop and was incredibly helpful in understanding the preparation for participants, the setup of the venue, accommodations made for load shedding[8], positioning of recording equipment, and gaining experience in co-facilitation. Though each workshop was helpful separately, the themes that emerged were eerily similar and have been synthesised in order to concentrate participant voices and highlight the robust discussions that occurred.

6.3.1. Equipping parents to navigate exclusion

On the surface, when the interview clip was heard and the story was read, the first thing that came up in both groups was talk around how to equip families to cope in communities when faced with situations like these. I was not surprised when we landed on this so early in my journey, it would have been where I would have ended up too. It was important to acknowledge the care and concern behind their suggestions and explore what this meant. The discussion ranged from educating parents on their legal rights to teaching them how to set healthy boundaries, and giving them the skills to de-escalate conflict, have crucial conversations in high intensity situations (as all the families had experienced), and to be better prepared to advocate for their children. It wasn't just intervention for the child but support for the parent.

P.M, as psychologist, mentioned equipping parents from a legal perspective, and helping them understand what could and could not be done to them or their child — a valuable contribution. She said "In my psychology profession, what would be best for Ncebs and her child is to equip her with skills to kind of teach her how to manage a disaster before it happens. It's almost as if we have to teach her that these are your rights because you have a child with special needs. You can take this route. You can ask 'this is my child, she's going to make certain sounds, can I please go through first?'. We can kind of equip her with skills to be the advocate for Aliza".

[8] An ongoing period of widespread national blackouts of electricity supply

The general sense of the participants, summed up accurately by T.G., was that "actively equipping parents to navigate these situations and modelling for people is necessary all the time". Generally, it was these two things that they discussed first: 1) that parents need skills on how to navigate exclusion, and 2) by parents modelling how to interact with their children in public spaces, they are effectively engaging in passive teaching for their community.

The additional challenges came with equipping parents who, for their whole lives, have experienced power dynamics that have damaged their confidence and ability to fight. It is something we all experienced in our community service years. C.W. had this reflection in our pilot workshop: "What I have noticed culturally, even if you look at hospitals and stuff, patients can wait five hours in the queue and not complain or question it. She [Ncebs] might not feel brave enough or have the power because she doesn't feel worthy or powerful enough. You are taught to be submissive and be quiet and follow the rules". A sobering thought.

We speak about equipping parents with advocacy skills but sometimes it is a David vs Goliath level battle. It is an incredibly onerous tasks for parents to find this courage daily. It is the expectation of parents needing to be superhuman.

It was something difficult for the group to grapple. I gently highlighted the fact that while it was incredibly important for families to be equipped to handle exclusion, they were already heavily armoured on a daily basis and that giving them more tools meant that their armour only got heavier. Our initial reaction as health professionals is to go to our patients' families. There was agreement in every group that education was key though the overarching concern was: "You need the community on your side, you need their buy in before you can educate. Unless the person wants to be educated, you can't make them choose it". There was our first hurdle. To that I asked "Why not?".

It opened up a larger discussion about when and how we decided that learning was not a shared responsibility. It is something I think of often as well — how do you teach someone who is not interested in learning? But when you step back from this and look harder, you realise that we create society together. Community is only community because we have quilted it together just so. Civilisation requires managing, overseeing, and regulating to have a sense of homeostasis (Amponsah-bediako, 2013; Chalachanová et al., 2021; Chen, 2015; B. Watermeyer, 2020). Society has been constructed over centuries of melding cultures and establishing a norm that would be acceptable to the world (Halder, 2017; Lalvani & Polvere, 2013; Mashau, 2018).

In order to do this there are societal rules that govern us all; you must be polite, always remember your manners, apologise when you've done something wrong, make eye contact when you're talking to someone, and listen when someone is speaking. While these are the more explicit social conventions, there are ones that are unspoken, rules that are unwritten.

Neurotypical society (that is also usually heteronormative, patriarchal, and colonial) sets up hidden expectations all the time that tend to trap anyone who isn't neurotypical, effectively othering them (Kraemer, 2023). Inclusion is then a group activity. Just as easily as society has constructed these rules, so they can construct a few more. Parents can advocate for it, but they cannot create it without the people around them. Community is man-made so let's remake it. So how do we overcome this new making and access community? Community is not a simplistic concept, it is an intricate web of people and institutions, geography or maybe shared experience, knowledge and culture. Once we opened that up, down the rabbit hole we went.

6.3.2. Education

Education was the consistent theme. The key to change seemed to be education. Our education, the education of others and where the responsibility of that education lies for those receiving it and those providing it. If people don't know, how can they know better? We swung like a pendulum from education that would have a generational ripple effect (start with the kids, the kids can make a difference) to targeting the community, the average joe on the street who doesn't know but should know; to allowing this education to be embedded into vocational training and tertiary study so that, from the very beginning, professionals, employers and employees can know better and do better. I will explore our various journeys below.

6.3.2.1. Who bears the responsibility of Education?

In an initial narrative to open the workshop, Sarah reflected on an experience she had with Ollie during COVID. He had been vomiting for three days when they had to take him to the emergency room. When they got to the hospital, Sarah explained to the nurse that Ollie had Down syndrome and that he was non-verbal, which he was at the time. The nurse proceeded to ask Ollie a barrage of verbal questions including when his last meal was, what it was and if he could taste his food. Sarah was a bit perplexed, rightly so. For her, the lack of understanding on the part of medical professionals was not something new but each interaction like this required education and educating fell to her. There is an exhaustion in having to shoulder this responsibility time and time again.

It brought the limitations of the medical model of disability, in this medical establishment, into sharp relief. The medical model itself does not just come into play in medical settings. It is pervasive with serious consequences. It minimises a person's life and reduces it to a diagnosis. It's likely that the nurse would never hear Ollie's rendition of *Shake it Off* and what a loss for her. When you see a person as their diagnosis, you fail to understand what they need as a human. In this nurse's need to gain information, she neglected to cater to Ollie's communicative need in order to do so. Time is of the essence in crowded waiting rooms with overburdened health professionals (Van Rensburg, 2014; Mophosho, 2018; Pillay et al., 2020; Wylie et al., 2016). But, is there no time to stop and listen?

Ncebs' story once again came through with incredible perspective for those who heard it. C.W. shared: "When I first met Ncebs, I sensed that she was a serious fighting mom, she was strong and assertive but also kind and gentle. I'm just thinking that she's probably constantly on edge and constantly wanting to defend, defend, defend. Even advocating must be so hard. We're just hearing one story but it this probably happens on the bus, on the taxi. It must be a constant thing because Aliza is so outwardly disabled. It must be impacting even her personality and who she is, needing to fight all the time. I just think of her every single day coming to fight and deal with those negative experiences. I wonder about the toll on her health. There is never an end to it. There is never a reprieve from having to be on guard or having to fight for her daughter." It was the recognition of the burden and the isolation that exclusion can have on a family.

From a professional perspective we spoke about where our role lay outside of a textbook. Each person's journey was so varied and unique and yet somehow we all ended up sitting around a table talking about change. Sarah and I shared a bit about our relationship and background of our journey together from being a therapist and a parent to becoming part of their community. With Ollie, his communication was so all-encompassing, it was a natural progression for us to talk about various aspects of his life.

I knew when his grandma was ill because Sarah needed help on how to explain it to him and needed support on ways he could express more complex emotions. We spoke about the kind of cake he wanted for his birthday. The first time he could tell his parents he was afraid of the dark was a momentous milestone for a sleep deprived family.

Sarah summed up the discussion artfully when she said “We felt it was our responsibility to educate our community to be able to communicate with him. Our community, our church and our friend community, use Makaton and have used Makaton for the last seven or so years. Where does your responsibility as practitioners end and where does community responsibility start? Or is it linked?”

We didn’t have any definitive answers but we had some directions about our next theme that K.P summed up: “It all boils [down] to education and how people are taught and awareness, because it made me think of how much of what we’ve talked about can go into training”.

6.3.2.2. Education and Training within Professions

This raised an important theme for the therapists and professionals involved in the workshop. They all reflected on their university experience and the lack of preparedness they felt in their degree. R.B. shared her experience of this from an educator perspective: “When I was doing my degree, we did a special needs module and I was very dissatisfied. It was so textbook, I felt like there was so much more to everything I was reading and then after reading I was like ‘how the hell do I put this into practice?’ Because it didn’t prepare me for that until I started working with special needs [patients].”. We joked about her module. Her single module in her four-year degree that would teach her how to work in special needs education.

The lack of preparedness coming out of university meant that sometimes practice created tunnel vision that clouded our view of the individual in front of us and often allowed us to neatly reduce a child down to a diagnosis. The textbook chapters that focused on the medical diagnoses of various disabilities could never show you how Ollie loved *Captain Underpants* or how Aliza knows her mum is near by her smell. It highlighted how our immersive experiences were our biggest learning and that our academic focused degrees did not prepare us for the nuance of working with disabilities as K.P. so succinctly put: “Finding the skills is not me opening a textbook.”

Similar feelings were echoed for L.N. when she said: “At university you’re never really taught these things, yes we work in community, but it’s a six week block and when you go, you leave, you’re done. You finished that module and you may have helped that child and you may have tried to educate the community but then again you are educating that community in English or your broken Zulu and you’re not sure what is being understood so what have you actually done?” She raised three important points.

1) The limitations of the grounding of our education where modules and grades take pride of place over learning the skills that allow us to embed ourselves in communities. Little thought is given to strategies that allow new SLTs to form relationships, shift power and connect meaningfully with those in the environments they work one. It's a block, it's ticked off and then it's done.
2) The communication breakdown that occurs when the diversity of our languages are not respected. We have a module or two of isiXhosa or isiZulu but this allows us to essentially greet our patients let alone be able to engage with them. Our professional training limits us when it comes to working in communities.
3) The notion that learning was a one way street as a professional. While SLPs can educate the community, what time is taken to learn from those communities? Professionals are not trained to think of learning as a two way street — especially in that community service year. There is so much pressure to be a consummate professional when you are the only therapist for 100 kilometres.

One therapist reflected on how she basically learnt to be an OT on the job. She attributed her learning to her role at the Developmental Centre she worked at for the past few years. It has made her the therapist that she is. She considers herself lucky to have been in an environment that nurtured her thinking outside the box and not having any preconceived ideas when it comes to disability. But would she have been this therapist without this job? She reflected on this field of disability in particular and the need to wear multiple hats. There is vital need for OT involvement in many spheres of a child's life but none of the participants felt prepared to support them once they left university. Textbooks meant to educate were just reminders of shortfalls and inadequacy.

There was also a worry about power imbalances and getting buy-in from communities when T.J. reflected on her concerns: "My worry is that it comes across as: you've brought in the white coat to teach us how to interact". There were concerns about backlash on families who brought in therapeutic supports into our community, which in itself highlights how tenuous and fractured our relationships are with communities at present. Practice shifts that empower therapists to manage power dynamics are key for the confidence of the therapists and the effectiveness of the intervention.

6.3.2.3. Education for The Community

This solution, it seemed, was also a double-edged sword because in many ways education can be a barrier. Families are willing to tell their stories but what impact would that have if the community wasn't willing to engage? Which ultimately came back to us finding a way to educate communities by getting buy-in, developing training programs for businesses, and changing policy. From a grassroots level we spoke about policies like White Paper 6[9] and how, for too long, it has laid dormant. It exists like a phantom, intangible and sometimes downright mythical.

A lot of the tone of this conversation was hypothetical as almost all the participants struggled to understand how community could be educated going back to the responsibility of it all. Not having buy-in from community members was a big concern. But the lens that participants were using was a *shifting* of a burden, not a *sharing* of a burden — a distinctive difference. It highlighted the need for partnership for the purpose of co-creating inclusion and belonging. Yes the community has a lot to learn but there is also a lot to be learnt. When community is such a multi-layered construct, you cannot assume that learning is a single lane freeway. Education most certainly includes capacity building that focuses on creating understanding and building trust. In some ways, there is also a measure of human nature where partnerships are built through advancing one's own mission. That's where the stories come in. If you want Ollie, Yusuf, Aliza or Tate to find a place where they belong, then receiving an education is easy because you are advancing our goal. The stories create the mission.

There was definitely need for change at those levels but our discussions brought us closer to home and our communities. We spoke about the role that culture can play in education with a few participants sharing from their own backgrounds and experiences. We all agreed that education of communities was essential. T.G. spoke to the nuance of learning in a culturally diverse population: "What I recognised is that we're so different culturally and I think specifically in SA. What I've grown up learning is one thing and then suddenly I see something different that I've never been exposed to. I'll never understand how to react unless I've been taught that it [the situation] needs something different to what I know. Something different is okay."

[9] A policy that outlines what inclusive education and training systems are and how South Africa intends to build them

There is an importance here in recognising that South Africa has been built on difference. There is a unique opportunity for learning and cultivating acceptance because of the diversity in the country. There is time, space and energy to experience difference, if only we embedded ourselves in community to learn from our neighbours, their neighbours and beyond.

Teacher R.B. spoke to the fear of the unknown. The fear of not knowing how a child will react in a new situation and sometimes the generational biases that exist in the present: "Every parent, Indians especially, a lot them struggle, a lot them don't have the support that they need to move forward. They are unable to get the help that they need because they don't know. They don't know what help is out there and often they're afraid to ask".

It is here that the importance of embracing our intersectionality as therapists would make a difference. For this Indian family or for the coloured family mentioned above. There are so many therapists with varying backgrounds that have the potential to connect with families who are struggling to find their way and who have intimate knowledge of the intricacies of specific communities. We are painted with the same professional brush when we study and some of that identity is lost.

6.3.3. The Power of Stories

While analysing the data of the workshop, it was clear the way that stories opened up discussion and inspired change — the evidence was subtle but strong. Like a star you know is there but you can't always see. Stories can be an illuminating moment, a thing of awe-inspiring beauty. Stories inspired other stories. For T.G., she had a personal story to share: "I have a cousin who grew up with a learning disability and his parents just decided to take him out of school. And it's one of the most difficult things he is experiencing now, he can't find a job because he didn't finish school. It was possible but it was hard. So it was easier to take him out of school and try to look for temporary alternatives and there are none which means he's suffering now. Different means exclusion in my community. Especially in our coloured [10] community, especially [for those] with special needs. The idea is to hide your child.".

[10] refers to members of multiracial ethnic communities in Southern Africa

In her many years as an educator she says she has been bolstered by the number of coloured families she has seen come through the special education system. Their presence represented a shift within her community that it was okay to come out of hiding and she is so encouraged by this as it makes space to create new norms. She has seen how the strength of one family is contagious and gives other families permission to be brave as well. The power of sharing a story.

I read an article recently entitled *The Power of Narrative: Change the Story, Change the World* (O'Donovan Phillips, 2020). It spoke deeply and truly to the precipice we stand on here. Change the story, change the world. In it the author spoke about the power that narratives have to give us a sense of belonging (Landrum et al., 2019; O'Donovan Phillips, 2020; Sium & Ritskes, 2013). The lived experiences of the people we work with serve as a powerful roadmap for us to be able to meet an actual need and not just a perceived one based on a diagnosis.

6.3.4. The Necessity of a Practice Shift

Our practice as therapists is another theme that came up frequently. There is a lot of discomfort in questioning everything you know. It requires rethinking, unlearning and relearning. We felt like we needed to break free from the chains that bound us in traditional practice because, whatever way we looked at it, our practice placed the burden firmly on the shoulders of our patients' families.

We spent time making sure others were comfortable with difference of one child with a disability when, really, the minority should not have to take on that responsibility. It is only natural to default to what we know. It is only human to search for similarities to unite us. But when that need for similarity requires others to hide who they are and exclude from environments, is that the kind of human we want to be? It was with absolute joy to me that one of the OTs, K.P, presented this as a solution: "I think therapy needs to happen outside of four walls. Outside of the therapy room, outside of the classroom." The power of stories was definitely a contributing factor as she said: "It is just horrific that a mum who already has so much on her plate has to walk into a place that we walk into every day, not knowing if she can just do daily things, do what she needs to do, because of what other people might say or do."

A lot of our practice put our skills into boxes. The institutions responsible for our learning enjoyed helping us fit into boxes: paediatric, adult, burns, hands, speech disorders, disabilities. We all knew we wanted to be one thing once we left university but we didn't really know how to be that singular thing. What we felt we needed was innovation, to think outside the box. A lot of intervention for us meant adapting a spoon with a yoga mat or laminating a core board for the swimming pool. Community is a box you tick off on a way to obtaining that all important degree scroll. When practices are run as businesses and therapists are bogged down with being administrators, debt collectors, and CEOs, the purpose of what we do is lost because according to medical aid rules and tariff codes, even one minute makes all the difference. It is the difference between a 16–30 minute session and 31–45 minute session (Discovery Health, 2024).

These were small real life needs that nobody really taught but that needed doing all the same. R.B. summed this up well as she said: "I don't want to see it on paper. I get that certain things can be on paper but I want more. I want to see and I want to learn. Working in special needs is what helped. That's more than just what's in the textbook."

On top of this, we were guided by norms that only matched a small percentage of the population and most certainly not a South African population. There was no accounting for the climate of our culture, the variety in our language, or even the scars of our past. Our professions were constructed in the Minority World, it is no surprise, the mould does not fit the Majority. For the participants it was difficult to wrap their heads around not having a yardstick to measure progress. There is no roadmap for decolonised practise.

How do you know what goals to set when if, for example, play means something different to everyone. What would happen if we accepted that instead of moving through the stages we know and love? There was fear of rejection of not being the gold standard. Meaning that if we were to make these changes, we may not meet the western standards expected of us. The question, then, was: What would it mean to pilot this way of doing? To me the answer was clear, that if we listen to our families and we did our job as communication specialists to give children and their families the voice to set the standards we adhere to, then setting goals are easy. The goals should not be ours, they should be theirs. We stood on the precipice of a rabbit hole that felt like we could be unravelling society with our radical acceptance.

Sarah's perspective remained invaluable. Two participants shared a story about their interactions with Ncebsi running into her at a shopping mall, seeing her laden with bags and carrying Aliza, and then stopping to take her out for a hot chocolate and sharing the load. To this she said: "What you did, the two of you rallying around her. You made an unsafe space safe, hopeful. And that sense of belonging came quite quickly. And so [that is] how community can shift our experience of what's safe versus what unsafe is." It made us feel like we didn't need to have all the answers up front but that these little acts of connection were the made waves we are looking for. These were important pedological principles to consider along with that of our mutual learning throughout this process (Fletcher & Ní Chróinín, 2022).

At the end of the day, we decided we could only make the changes that needed to be made if we worked together. My feelings were echoed in the participants' closing remarks, some who had shown beautiful growth in the session by accepting the challenge of unlearning, rethinking, and relearning. Whether this was a shift in perspective or a call to action, the workshop proved to be the catalyst for a ripple, after all one tiny drop is all you need. Our brains were tired as we went around and around but our passion was fuelled.

We thought about the need to draw in more stakeholders into our practice, we dreamed about developing training that could reach teachers, sales assistants, waiters, security, airport staff, policemen, paramedics, hospitals and all the people that a child would need. However, at times it felt overwhelming knowing where to even get started. How do we shift power dynamics enough to place ourselves into communities respectfully and humbly? Is that even possible? Part of this challenge is that there is little that we know as professionals as to what is already taking place in community spaces and who the key roleplayers are in everyday situations, especially as his changes from family to family.

There is sometimes a complex that accompanies this therapeutic space — the saviour complex. It is one we only lightly touched on but one I am quite cognizant of when engaging with these discussions. It is so subtle, the line between supporting and saving, and when we spoke of power dynamics between professional and client, we didn't think of the power dynamics between "saviour" and "saved". Allyship is a tightrope for therapists to walk and requires forethought, empathy, and the ability to stop and really listen to the need.

6.3.5 Live Loudly

The crowning jewel of this workshop was when one of the psychologists emphatically pronounced that our patients and their families should just Live Loudly. That they don't need permission to take up space: "What I'm trying to say here is almost living with Ollie loudly so that anyone who is looking can have their own questions answered about him. So if you're taking him to the grocery store and you speak to him in the way you normally speak to him, that encourages him, that makes him happy, that makes him respond, he will do that. The person that's looking has all of this going on, seeing the whole process. By the time that person comes to you, if they want to approach you, a lot of questions would have already been answered. You need to live with your child, the way you want them to live and everything else will just fall into place. You can't teach everyone, but you can carry on living". This resonated with all of us. Though we didn't have specific answers, and the thought of reimagining all we know is exhausting, small shifts like simply being — living their full lives — in communities and having that be accepted was enough. In this way, we could easily find ourselves being part of this kind of change.

We reflected on our journeys and how important we can be in setting examples for others. KP reflected on her own experiences: "Creating moments of similarity and connection are important and I know how to do it, but when you're in a shopping centre, how do you do it? You learn from how somebody else models. I know that Checkers has employed people who are deaf and I have learnt from watching how the other employees interact with them to know how I need to interact. Even though I have training by the way, it's not because someone stood in front of me and told me what to do. I think it's the exposure. I think we can do that every day." Despite dismantling our professions, we all agreed that this was something we could work with. We could be examples in our communities; we could be advocates in meaningful ways and also work from the top down — we could be the people who teach the employees at Checkers how to communicate alternatively and, in doing so, empower others through their daily actions. It was a web of education and advocacy and our presence in communities.

I leave you with this final thought from Sarah. I want to frame it and put it on billboards. I want it to be part of every curriculum because at the core of the project, this is what matters:

"Where I have felt safest, and where I have felt like I have belonging in the therapeutic environment, is where people tell me I don't have to advocate for him (Ollie). I advocate for him externally, but when we are talking about SLT or OT or physio or the education space. Where I feel safest is where somebody says 'You don't have to explain.' If he's having a meltdown, don't worry, it's okay. I don't have to go like I do externally 'Oh he's going to shout at you because he is feeling overwhelmed.'

In the therapeutic space where I have felt people come alongside me and build community with me is they ask me how I'm doing not I'm focusing on his talking, his walking or his fine motor skills. It's just how are you? And it's not a therapy session — I'm not asking for therapy but it is a sense of 'I see you and I know this is hard', *that* conversation. And then it's me not always having to explain away his behaviour even if you don't get it. I'm not asking you to get it all the time. But when I have that sense of inclusion, belonging, community is when I am seen and I'm heard because I fight for him in every setting — I could give you a million and one examples. But the places where I feel seen is where I'm heard and seen and where they care about me and him."

Chapter 7 – Thesis Building: My Undoing and Remaking

This chapter is the culmination of years of discomfort and a journey trying to get to the bottom of that feeling of knowing something was missing. I have loved my 10 years of practice that have grown me and challenged me. This chapter will explore my reflections as well as key concepts that came up over the course of my expedition; including the necessity of our evolution as a profession, current barriers to our practice, and decolonial ways of doing that are vital to providing culturally responsive services within a South African context. All of this will be explained within the context of the narrative analysis and the workshop learning.

7.1 On the Inside Looking Out

There is a movie quote that comes to mind when I think of my journey so far: "I'm in a glass cage of emotion". It is meant to be comical, and it really is. The character in the movie is stuck in a phone booth, banging on the glass in the most dramatic way. Right now it's feeling really poignant for me. The journey of this PhD has felt like it has turned me inside out, upside down and stretched me in all directions.

And yet, I feel like I am in a glass cage of emotion when I think of my future as a speech therapist. It is a constant rhetoric; while I am brushing my teeth, washing my hair, sitting across from carefree little boys who couldn't care less if they can't say "s" but whose parents email me at least once a week to check on their progress. My job is change — change the way they talk, change the way they communicate, change the way they interact. It is never about changing me or the world around me. I think it is time for some deep and critical introspection as clinicians. I think we need to turn our gaze to the practitioner.

So yes, I am stuck within the confines of being an SLT. I stand in this glass cage, looking out and seeing all the possibility of practice that is fresh and exciting. But the cage is fragile and it is made of years of positivist evidenced based practice, western ideals, Minority World Knowledge, cultural and linguistic homogeneity. The cage represents the fragility of the profession. It is able to trap but it also holds a reverence that is not easy to break. The concepts I have presented here before you are not new to the world, but they would be new to SLT. Our glass case has kept us too sterile; the outside world is complex and messy and difficult to navigate but it is real; it is where our children live and we need to meet them there.

The concept of inclusion is not novel, but it is rarely acknowledged from a communication perspective. Legislation and policies are definitely powerful driving forces behind inclusion but what does that matter to the man on the street who has never read the *Convention on the Rights of Persons with Disabilities*? Inclusion also needs guardians on the ground to plant the seeds of belonging and to nurture them until that grows. Communication is as evergreen as they come. It is constant and it is connection. As SLTs , we are sometimes so grounded in our medical history that it is hard to look forward to a future that might contain more humanness; something less clinical. But maybe we should be. It is okay to start dismantling the cage — while it keeps us in, it also keeps others out. Perhaps dismantling practice is a way of opening up the profession to the world at large.

7.2 Taking off the expert hat and navigating Power Imbalance

For most of my professional career I have been hailed as an expert around speech, language and communication. In my earliest days I argued against parents' wishes for their children because I believed I was right. The evidence was behind me and I was the professional who knew better. In one instance it was a mum who didn't want a PEG Tube[11] inserted to prevent her baby's obvious and life-threatening aspiration. How irresponsible, I thought. How cruel and uncaring a mother was she. But they didn't have running water at their informal settlement. And how was this mum supposed to keep the site clean and sterile and prevent infection when accessing clean water took hours of her time? How much would it cost her in monthly hospital visits to collect the formula needed to feed her child when her breast milk was freely available? The memory still makes me shudder.

Over the years, it was easy enough to acknowledge how much I didn't know. Once I broke free of my clinical bonds that holds fast to all new graduates, it was easy to focus on connection first. Power dynamics have long since plagued the profession and remain a barrier to community practice (Abrahams et al., 2022; Keikelame & Swartz, 2019). As long SLPs are positioned as the only experts, there will never truly be room to create partnerships (Berenguer et al., 2022; Hyter, 2014; Marshall et al., 2017a). There is so much to be learnt from community if the profession is willing to take off the expert hat and surrender to gaining knowledge from others (Donaldson et al., 2023; Llorens, 2009; Preece, 2013).

[11] A small hollow tube that goes into the stomach through the abdominal wall. It is generally recommended as an alternative to oral feeding when there are difficulties with eating and drinking.

7.3 Reframing the Evidence

One of the most liberating experiences of this project was conducting the narrative interviews with families. As we talked, goals starting forming without me having to complete a checklist, fill in a form, or dissect the child into all their deficits. Goals that we were creating together; that had meaning to each family, that weren't just another piece of homework on top of balancing work, life, therapy, and family. The goals that emerged were woven into the family and not being imposed by my expert self. I could see that these families would be able to sustain them because their co-creation meant that they had ownership and autonomy.

If anything, this experience highlighted how assessments pigeonhole children into predetermined outcomes. But if we didn't take the time to listen, how would we know that Tate's dream job is to be a pilot or that Ollie's key motivators are music and a frozen beverage.

When we reduce a child to their assessment results, we miss out on the most vital guidelines they are giving us by showing us who they are. There is no greater evidence than that which helps us help our children be their most authentic selves.

Evidenced based practice was my mantra coming out of university but I think what was once a guiding lifeline soon became a shackle when I started to question where the evidence came from, who was curating it and who continued to drive its progress. The entire basis of my degree starts to unravel and it is an uncomfortable space to be in. I feel like I am disrespecting my life giving "parent" that has provided me with a career, food on my table, a roof over my head. But I am also excited to reimagine this profession that I love in new and interesting ways.

It is time to start creating new evidence, frameworks, and lenses so that we can shift our practice into the 21st century. There are other ways of knowing that are just as impactful and evidenced based but that prioritise the voices of those who experience or have experienced communication impairment. For too long the profession has centred practice rooted in western theories and research that grounds numbers and statistics over lived experience.

The workshop experience showed me that the connection we have to stories is overwhelmingly and astoundingly powerful. Stories have the power to transcend cultural and linguistic barriers, and to broaden our focus and allow us to pursue true communicative participation for our children. We all have that story we hold on to, that child whose face we cannot forget, that family we feel like we failed or the family with whom we have shared tremendous joy. Those stories, whether in grand or minute ways, have influenced us enough to change the way we do things.

Maybe we ask a question differently now, or play a game in a new way. Perhaps we are able to let go of the structure of our practice and let these families show us the way. Often the way we are guided is outside of our therapy room. It is time to make friends with our discomfort and follow it out the door.

7.4 The necessity of evolution

Much of the feeling of worry and unease came from feeling stagnant. What excited me about the profession initially was the endless opportunity. The ability to chameleon into every environment and be whatever was needed — in neonatal ICUs, classrooms, stroke wards, or non-government organisations. The possibilities were endless. And then all the walls of these institutions started closing in, and it felt like they were suffocating me while keeping so many out.

The more experience I got, the more the colonial nature of the practice seemed stunted, ineffective and frustrating. We are creatures of habit, so change is often unwelcome but without careful pruning, we cannot expect to flourish. Not changing means, we lose touch with those who need us the most and that is something we just cannot afford to do.

Our first real taste of change that rattled our foundations in speech therapy was the recognition and acceptance of different neurocognitive styles. We were taught to question our standardised scores and developmental milestones. It looks at not fixing any child who is different but moulding the world around them to understand these differences and give them tools on how to navigate it.

We questioned why we needed to teach social skills to the minority when the majority had an equal, if not greater, responsibility for understanding, patience and acceptance. In this way, the burden on the minority to fit in is lessened and the load is shared amongst community. For families like the Rogers and the DaCanhas who were steadfast in identifying who their community was, there is immense comfort and relief in being able to share their hardships, grief, triumphs and joys.

In small but effective ways, there are movements like these being made with AAC. It was glorious and freeing and, for the first time in a long time, I didn't feel alone in thinking we had room to grow. And there it was once more, that spirit of *ubuntu*, that collective exhale and the importance of having a community who just gets you. It was not the easiest time for a lot of us, and those of us buying into this different perspective were considered trouble makers and rabble rousers. We upset the status quo.

It really opened my eyes to the fact that maybe it was a good time to start thinking about looking for answers outside of the profession. It was time to step out of the cage of fragility that held us back and explore the work that other fields had to offer.

There are a few professional disciplines that run parallel to ours but never intersect. Fields like disability studies have, for many years, started looking at models and frameworks that explore social inclusion and unravel our norms. So inclusion is not a new or ground-breaking phenomenon, but exploring it through our communication lens would be. The concept of inclusion is built on many things. Often when we think of inclusion, it defaults to the physical. As a society we have made great strides in ensuring we have ramps to access buildings, toilets with room for wheelchairs to manoeuvre, and big enough elevators for ease of movement. But inclusion is so much more than just these physical adaptations, it is a much broader societal obligation.

It requires the in-depth examination of the barriers that are imposed at an attitudinal, environmental and institutional level, including policies and practices that can isolate and exclude those with disabilities.

In addition to this, research in these disciplines further explores the impact of educational, social, cultural, historical, political and economic factors on inclusion and exclusion. Furthermore, the focus is on optimising participation rather than requiring disabled individuals to fit into already existing but subpar arrangements.

Within the context of communication, this means that all alternative forms of communication would be understood and accepted. That others would have the knowledge and the skill to facilitate communication in a way that wasn't just around speech.
The overwhelming feeling is that it is not the disability or impairment that limits people, but rather the barriers around them. This is a far cry from the impairment-focused nature of our profession, but just imagine all we could achieve by flipping our perspective to mirror this and shift our focus into community. Communication is one of our most basic human abilities that tie us into every experience we have in the world around us — the ability to see communication as it truly is; something that is a shared experience, rather than placing the onus on an individual and their families would make all the difference.

A lot of the current research looks into community development and how inclusion can be created from a grassroots level. To do this, listening to the dreams, hopes and aspirations of local communities is vital. Highlighting the stories of people who are disabled is at the centre of this approach.

While inclusion is a community movement, there is space and power to highlight individual lived experiences that nuance the daily struggles and triumphs of living with a disability while being grounded in a contextualised historical understanding, especially in a South African context.

This study has been a shining example of how individual stories, as different as they may be, can have common themes that bind them. For the families that participated, all of them struggled to find inclusion, all of them had to fight for it. All of them had to carry the burden of disability alone despite their unique backgrounds and circumstances. Inclusion is a kaleidoscope that is made up of a million different parts that come together to create something beautiful.

7.5. Our Barriers

Neurodivergent individuals are no strangers to the concept of ableism. It must be so conflicting, exhausting and draining trying to fit in to a neurotypical world when you are not wired that way. As a society, we have built standards of normality that guide the way we look, move, eat, speak and so much more. As an SLT collective we have created these norms and so, as a collective, it should be our responsibility to break them.

Community practice is something that has been explored in many other fields across the world from social work to disability studies. Even the rehabilitation sciences have dabbled in this space but research is limited when it comes to SLTs' involvement in such practice. This is particularly confusing when you consider that communication is such a community-based activity. We often use the term "communication partner" when we think about training for those who need AAC. We start with the families and the teachers and then perhaps we get the extended family on board.

But we often put a limit on who these communication partners are and how we train them. On a daily basis, I speak to my mum, dad, brother, and colleagues at work. They know me and my communication style and they are the most important to me on any given day. However, the other day I needed a locksmith and every time I go to the supermarket I am faced with a different person behind the till. Sometimes we speak about the weather, at others we talk about the war on Gaza, it just depends on what's going on in the world. It is often on my mind how people with communication impairment face these random daily interactions (or what is often a challenge) when only a small handful of people accept and understand the way they communicate.

When we limit our focus to just the child and their family, we are leaving out the majority of communication partners that child will need to engage with in the future. Our biggest missing link when it comes to communication is community.

The stories of each family highlighted the isolation that they feel when their children are not understood or included. For Raeesah, it was a deep hurt to watch Yusuf stumble after the other children, knowing he couldn't keep up and knowing he couldn't communicate enough to ask them to slow down or wait for him. The isolation was eased for someone like Ollie. It took a long time for the baristas at their local coffee shop to understand that a "Peezo" meant a "Freezo" and for Sarah it meant that she needed to be Ollie's mum, advocate, dictionary and voice. But they did take the time and that made all the difference. At the forefront of my thinking is how, if we were more present in these community spaces, we are not just supporting Ollie, Sarah and the establishment, but any child or adult with a communication impairment who comes through and gets to feel like belonging isn't work.

Additionally, we start encouraging the family to take their communication device to sporting events, beach days, coffee shops and then we hand over the burden of normalising this kind of communication to them. When I think of Raeesah and her hope for Yusuf, it is not concern she has for herself as a communication partner but for others who do not understand Yusuf's alternative communication. Within a traditional practice view, I am basically overlooking this parent's greatest need by not looking outside of direct therapy and intervention. A community approach here would make all the difference to this family. Surely our role as communication experts means that we see the transition to its end and we focus on making alternative communication more acceptable to our wider community.

While there are many benefits, there are also risks. Engagement fatigue and burnout are ever present in the profession and, without the armour of four walls, there is a danger of getting too invested in a way that compromises professional boundaries (Brito-Marcelino et al., 2020; Ewen et al., 2021). Critical self-reflexivity is key for therapists to be able to maintain suitable boundaries while engaging meaningfully with communities (Harsha Kathard & Pillay, 2013; Verdon et al., 2016). There is the noise of life — the struggles of getting people to engage; of trying to navigate intersectionality with care and empathy while still structuring in communication goals (Sharma, 2007; Thambinathan & Kinsella, 2021). Though, in saying that, by owning professional identity, therapists would be able to engage with their own communities and practice in a setting that is safe and familiar.

Thereby allowing freedom to navigate these intricacies based on professional and personal knowledge (Abrahams et al., 2022; Thunberg, 2021).

7.6. Decolonial Praxis and Story-telling: An African way of Knowing for Speech Therapy

Decolonial Practice seems so accessible and so out of reach all at the same time. In theory, I know what can be done and what a brave and bold world it is when we dismantle our colonial roots. But there is also deeply entrenched imposter syndrome in innovating new ways of knowing. When all our direction, guidance and knowledge has come from the Global North, how we do carve out our path in the South without falling into our old ways,? Studies like these have the potential to create new frameworks, ways of thinking, and tools that help us down our old ones and trade in what we know for the unknown.

One of the core principles of decolonisation in SLT practice is breaking down the barriers of the medical model that forms the foundation of the profession. It means putting stock in people's lived experiences rather than a data set. There is so much that a graph or a table cannot nuance especially when it comes to something like communication which is such a deeply personal human experience. How would I have been able to synthesise and reduce any one of these family's journeys into a single statistic? The stories illuminated the need for shared experience, for human connection, understanding, and the need to hold each other up in times of strife and celebrate in times of joy. In their own way, each story highlighted the need for *ubuntu*.

Sharing information through stories is not a revolutionary practice. For hundreds of years, storytelling has been a way to share knowledge and experience in ancient civilisations. We even use it within current practice as a clinical tool for intervention. But I am hoping to harness stories in a different way by using story telling as a co-creating therapeutic measure in lieu of traditional assessments that actually give little information outside of where the deficit is.

For the purposes of AAC, there are many assessments that use checklists, observations, matrices and tables but none really highlight what it means for the child using the AAC or their family. Stories are sustainable, equitable, in depth and meaningful. We all have one to share. They can be shared in any culture, language and environment, whether in a state-of-the-art hospital, in a hall, or under the breeze of a palm. The only resource it requires is a listening ear and prompting question here and there. Of course, there is the argument of time. For us as SLTs our days are carefully crafted to the minute, tariff code and dependant. Time is money and for many, practice is running a business.

But having a tool in your toolbox that empowers families to become knowledge creators, an important shift in power, is one that money can't buy. Without this professional and familial alignment, our jobs are just that much more difficult. In the early days of my practice, I felt such frustration at families who wanted change and wanted to see a difference but who wouldn't put in the work I was giving them. I was only one person and how was I supposed to do it all. It took me a long time and a lot of growing up to be sensitive to families' capacity and how they prioritise their goals. True, time is of the essence, but when we create meaningful partnerships with depth and understanding, a shared vision and mutual respect, we will never run out of it.

7.7. Community and the Co-Creation of Knowledge

This means breaking away from our traditional SLT practice and being comfortable with exploring new ways to support our children and their families. One way of doing this is centering communities in practice with the child's needs as the framework for intervention. When we anchor our therapy with lived experience, it becomes so much more meaningful.

We need to be asking more questions around family, friends, hobbies, favourite foods, important places, key people — questions that help us understand who our little humans are because, until we know that, we cannot even begin to provide the support that is needed. We need the stories, the bigger picture.

For the therapist in the hospital, at the clinic or within a school, communication is essential. Wherever we are, we have community and so this should be our practice focus. Consider Ollie who had just learnt Makaton for his favourite foods. Consider him at a party trying to ask for them over the noise of music, talking, laughing, chaos. Consider that in the near future, he will be 16 and maybe he will want to order popcorn at the movies. What then? Who will he turn to for a translation? His family dictionary won't always be around. Who will look out for Ollie when they are no longer there is always at the back of Sarah and Gary's minds. Surely this worry is something we can share the load of? All they want is acceptance for their son and it is not something they alone can give him — that permission needs to come from us.

Consider an adult who has just had a stroke and spent a week in hospital. Who do we empower to take care of them once they leave that bed? The family always, but what about the neighbour that drove them to the Emergency Room and the aunt that has been watching the children while this family has been way? That is the most invaluable web of humanity.

South Africa has a rich tapestry of community like this, woven with the spirit of *ubuntu*. These are the people who could make all the difference in sharing the load and, through connection, help this family find their new normal. Embracing *ubuntu* as part of our practice means that we can focus holistically on the person and their community rather than focusing on the detached and the clinical. These roots of humanness should be grounding us — we should not be afraid to centre the person instead of their diagnosis. We need to focus on connection and community rather than our pathology.

I don't mean it in a way that is *kumbaya* and campfires. Humans are not known for their effortless kindness toward their fellow man. But *ubuntu* is that woman on the taxi who invited a stranger and her daughter to live with them when they had no place to go. It is the big and small acts of warmth, care and compassion that deeply impact other human beings.

7.8. Linguistic Justice and Giving Power to Alternative Communication

Linguistic justice refers to the right that every human being has to communicate in a way that is comfortable and meaningful for them (Kasnitz & Block, 2013; Soler & Morales-Galvez, 2022). It is a concept that can be used to build multilingual and multimodal expression that is more than just speech and oral language. While both of these are vital for the evolution of practice, connection to language is a vital part of forming identity and it has been taken from many communities in the process of colonisation. It is time to give this power back. For professionals whose careers are based on the understanding and building of language and communication, this is something we rarely focus on.

We cling to our power as professionals so much that we are rarely able to share it, let alone give it up to empower another. When I think of my initial practice and focus of intervention for all these families, I see it as very one dimensional. There I was an English-speaking, middle-class therapist providing therapy to families like Ncebsi and Aliza, a duo with immense complexity surrounding their communication needs as well as their social and economic. For parents like Ncebs, she has always had to play the role of defender, soldier, and fierce protector. Giving her past experiences and voice power in carving out a path for Aliza means so much to her. It means that we are listening, doing our best to understand and that, at the centre of this entire process, is Aliza.

For a child like Aliza there was no box she could fit into, no curriculum that could encapsulate her need, no strategy that could contain her. Her intervention required a massive shift in power, positioning Ncebs as the expert and the therapists around her as the vessels to harness her knowledge and manufacture it into an intervention.

Giving vigour and recognition to Aliza's unique brand of communication, instead of imposing our own therapeutic ideals, meant that she had autonomy from day one. We went with what was natural for her — feeling, touch, gesture and sign.

In a broad sense, this is important for our South African context. With 12 official languages, English is still the dominant force amongst the profession. It comes with a history of political and economic shackles that are linked to colonisation and apartheid. If we unpack this concept even more, we can see how working toward language justice will help us dismantle what constitutes the "right" way of communicating.

Oral language has long since held pride of place in the communication world, minimising alternative methods of engaging. As SLTs, alternative communication is a large part of what we do and it should be a large part of what we advocate for.

For every single family in this study, alternative communication played a crucial role in unlocking their children's frustrations and fostering their independence, but each one has had to battle against the stigma of using a method of communication that was wasn't considered "normal".

Even the word itself, "alternative" separates this kind of communication from speech and marks it as something "other". One of the building blocks of inclusion and belonging is acceptance which is something we have the capacity to build when we reimagine our practice and work closely on awareness with our communities.

7.9. Critical Self Reflection: Soul Searching as part of Professional Practice

"Unless someone like you cares a whole awful lot, nothing is going to get better. It's not." – The Lorax

Another tool that is paramount to our evolution is our critical self-reflection. If this was not part of my practice, this project would not have been given life, so it is a powerful tool indeed. We all have our own stories and experiences that have shaped us and that influence the lens with which we view ourselves and our profession.

So much of our curriculum as SLT students is focused on professional identity of being the expert and conducting ourselves in a professional manner, but not much in the way of tying who we are to our professional practice. This entire project has been deeply personal to me. I think a lot of my desire to change and reimagine practice comes from a very personal place. All the other therapists I have spoken to that are involved in this work, the disrupters, have similar characteristics of this kind work being more than just a career.

This is difficult to navigate in a profession where burnout rates are already so high — adding humanity back into practice can be daunting.

But surely that in itself is a huge indicator that something needs to change. Changing practice can shift the rat race of appointments and billing and give us space to find out humanity again. Unless this work is meaningful, nothing will ever change. We do the work but not empowered to shape what the work looks like; but we can start taking that ownership back now. Establishing individual professional identity will be a key part of the professions growth as it allows therapists to bring who they are to the table.

7.10. Conceptual Framework: The Invisible String

If anything, the journey of this thesis has shown me how interwoven communication, inclusion and belonging can be. It has highlighted the power that speech therapists have to bring these concepts together using community as the invisible string that binds them. Visual representation is key in tying all these complex concepts together (le Roux, 2022). The framework I am proposing is a patchwork quilt.

On one side of this quilt, we have our families. To consider communication is to consider their language, culture, history, race, gender, geography and all the little threads that make up the fabric of who they are. Each thread of intersectionality is different and creates a pattern unique to each family. On the other side we have decolonial practice and new ways of doing. From a communication perspective they are linguistic justice, story-telling, decolonial praxis ,and critical self-reflection. These, too, weave an intricate pattern that is unique to each therapist.

This framework highlights practice in a way that is not linear, simple or as reductive as it can be. Each therapist will have their own quilt by the end of their career — a patchwork of pattern, colour, experience, stories, and when they moved on from the profession, they will have the most remarkable heirloom of their efforts. Maybe they hold on to it, maybe they pass it on for it to grow, for a new hand to start threading new squares. I think this visual captures the complexity that I have been trying to highlight. I went through so many visuals in my head but none that applied so wholly. I thought of a tree but growth is not always linear; I thought of a human chain, but how would you represent the uniqueness of each human in a single illustration. There needed to be a way to tie all of these incredibly complex concepts together and highlight how big our role is in uniting them. So here it is, my Invisible String.

The Invisible String creates a metaphor of a thread that binds us. The string collects our identities, our backgrounds, our histories and realities and joins them with our decolonial driving force. Upon reflection, the string not only helped me to analyse my data but conceptualise this entire thesis. Each family had their own nuanced patch, heavily influenced by their own experiences and own intersections. Each story had their own tone, their own spark, their own beginning and end. There were socioeconomic differences, embedded racism, bigotry, hope. Their stories were moulded by internal and external factors each resulting in their own pattern that speaks to their unique experience. Community is that oh so important strand working its way through this intersectionality – it crosses divides, it acknowledges differences and ultimately, it has the strength and power to bring us together.

POWER IMBALANCE
COMMUNITY + THE CO-CREATION OF KNOWLEDGE
STORYTELLING
REFRAMING THE EVIDENCE
CRITICAL SELF REFLECTION
DECOLONIAL PRAXIS
LINGUISTIC JUSTICE
GIVING POWER TO ALTERNATIVE COMMUNICATION
Community Con
COMMUNICATION
SLT
LANGUAGE
FAMILY DYNAMICS
CULTURE
RACE
ACCESS
DISABILITY
GENDER IDENTITY

Chapter 8 – Conclusions and Recommendations

8.1. Conclusion (Is it?)

This project has been one of my greatest stressors and biggest joys. I have so deeply enjoyed this entire learning process. Back in 2021, we had our first in-person project gathering in Cape Town. I remember my first decolonisation learning seminar and feeling so overwhelmed by what this concept meant, what it looked like in practice, how it applied to me and how on earth I would ever understand the place it would have in my learning. It was not a train that came at me at full speed, nor was it as graceful as a flower in bloom. It was a little golden thread that wove in and out of my life lighting up moments of change in the most subtle ways. It was a discussion where I got to ask a question that allowed someone to think differently; a conversation with a parent where we connected instead of pathologised; it was the freedom and letting go of being the expert. It was many intertwined moments and shared experiences that continue to shape who I am. At the end of it all, I feel as though I am sitting on a precipice, the edge of a big exhale. Now more than ever, I am convinced that this is the future of speech therapy. It is such an exciting thought that our profession can be made and unmade, and that there are other lenses to view what we have always known. That we have the potential to evolve and there is space for people to tell their stories within the power of community. We are at a crossroads and it is the most invigorating thought. This is not really a conclusion — it is just the beginning.

8.2. Strengths and Limitations

A key strength of this study was the study's rigour, in depth data processes and data triangulation through multiple processes including interviews, workshops and member checking. Though data was collected from multiple participants and methods, the findings reflected similar themes and key findings despite multiple viewpoints. Another strength is that participants had a previously established clinician relationship and were therefore able to delve deeply into their experiences and share their stories. While extra care was taken to separate therapist and researcher knowing that relationships had already been forged, the very human nature of this research could have left room for bias. The workshops though intimate enough to allow for every person's input could have been expanded to include a wider variety of professionals and potentially more SLT input as well as further community participation.

Though the invitation was extended to share their experiences, parents were more willing to tell their stories than community members were. Whether this was due to lack of relationship with the researcher, little connection to the project or simply a lack of time, the answer was unclear. This is an area to explore for the future as the focus is on community and inclusion.

Another limitation was the lack of exploration regarding Community-Based Inclusive Development (CBID) which is a collaborative approach that focuses on creating inclusive societies. Further investigation into CBID within the field of Speech-Language Pathology might open doors to multisector engagement and co-ordination that would be vital in repositioning the practice not just theoretically but practically as well.

8.3. Recommendations for the future

During the course of this project I have agonised over the "what next?". This work is something I am incredibly passionate about and could keep pouring myself into for the foreseeable future, but what that looks like can be a little hazy. There is a part of me that is worried that, in order to keep doing this work, I will need to leave speech therapy. That something like disability studies is a place that is ready and willing to receive this information and excavate more. Then there is a part of me that is genuinely excited about the work we have to do in our profession and I feel privileged to be a part of it. I owe it the families who have bravely journeyed with me and whole heartedly bought into the vision of inclusion and belonging.

The next stage of this study for SLPs should include further exploration of the practice shift. There is a lot here that is explored conceptually, but there are steps that can be taken to implement these practically. The workshop was an incredible learning but it was just a stone that was thrown to create a ripple.

The ripple now needs to be explored and practical strategies to support communication need to be championed. There are two focuses here that would be important, one on health professionals and the other on community. For health professionals, the learning from this study will be brought to the fore as the foundation of building ways of learning that open conversations and create change. Furthermore, there could be an exploration of arts-based methodologies for participants at the interview and/or workshop stages that allow them the agency to participate creatively, deeply and more meaningfully with the subject matter.

If each professional took at least one strategy away to help them reimagine practice then it would be a success. Similarly, a community workshop would be instrumental in further exploring inclusion and belonging, and putting into practice the co-creation of knowledge and sharing experiences toward a common goal of understanding. The door is wide open. What an exciting thought!

8.3.1. Practice Shifts

I think the implications on practice for the future is one of the key considerations to come out of this study. There is no absolute conclusion or single, irrefutable way of doing things. There are multiple options for practice shifts that can be unique to each professional based on their reflections and decolonising journey. Part of practicing critical self-reflection means that each professional needs to explore their own ways of doing and make changes that mean the most to them and their patients' families. In a profession where burnout rates are already incredibly high, thinking about humanising the profession can be daunting. But we work with humans and must keep this top of mind.

They are not just cases and diagnoses or words on a form, and treating them as such reduces their humanity as well as our own. For the moment, all I am proposing is taking a step further away from the medical model of disability that has formed part of our SLT foundations. This means seeking knowledge from the non-medical community and pushing to the forefront those who live and experience communication impairment every day.

Critical reflection is also key in supporting a practice shift. This process of reflection should be instilled in students as they make their way through their learning in order to create self-aware, culturally responsive therapists who understand their own strengths, biases, privilege and power. Current teaching practices are largely focused on students acquiring technical skills with little thought given to reflexivity.

As qualified SLTs, this reflexivity is equally as vital for the evolution of our own practice. There is no harm in examining our biases and worldviews and how these might influence our service delivery, especially in culturally diverse environments.

It is a transformative of way of learning, unlearning and relearning. It can be explored at a micro and macro level from the intricacies of our children themselves to the influence that history, politics, culture and economics weave into identity. It gives us the depth to examine the power we hold in our professional interaction.

8.3.2. Research

When I think of the future of research and the next steps, I think of the momentum this study could have if we kept going. Each phase of the study informed the next and branched into a new thought, a new way of doing and a new way of inspiring. Future research could benefit from longer studies that measure the levels of professional growth and change when practitioners are exposed to stories of their families and their communities.

This research would be two-fold:

1) to give power to the families and their voices on a large and meaningful scale, and

2) to support SLTs in their journey of professional evolution and decolonising their practice at an individual and small group level.

The dissemination of this information could bring about deeply effective awareness campaigns that bring life and a voice to "Individuals with Disabilities" who are often kept behind close doors or tucked away. For people in communities who have not experienced disability themselves, or who have not met someone with a disability, personalised stories have the power to move them to change.

Once you think of Ollie, Yusuf, Tate or Aliza, it would be hard to turn away from them when you know the most they could ever need from you is to accept them as they are and maybe try to understand them a little bit better. With a campaign like this, we could curate the most extraordinary human library in the spirit of *ubuntu* — once you've sung a Taylor Swift duet with Ollie, your life is forever changed.

8.3.3. Policy

One of the most exciting implications of this study is the influence it can have on policy and practice. Something that came through in the workshop discussion was the need for change to start from the roots. For professionals, this means influence over our training and embedding change into our curriculum. For our future, it means working with children in schools to raise new generations of inclusive and accepting communities.

For our communities, this means creating awareness in schools and in everyday institutions such as supermarkets, restaurants and recreational societies.

Global policies exist through organisations like the United Nations and the World Health Organisation but they are still heavily weighted toward the Global North and the research that takes place there. There is a desperate need for a policy refresh that is rooted in the South, decolonial at its core and co-created with the people that it impacts (Straus et al., 2009). Policy with these concepts at the heart have the power to influence curriculum at a school and tertiary level, employment, accessibility, and inclusion at multiple levels of our society.

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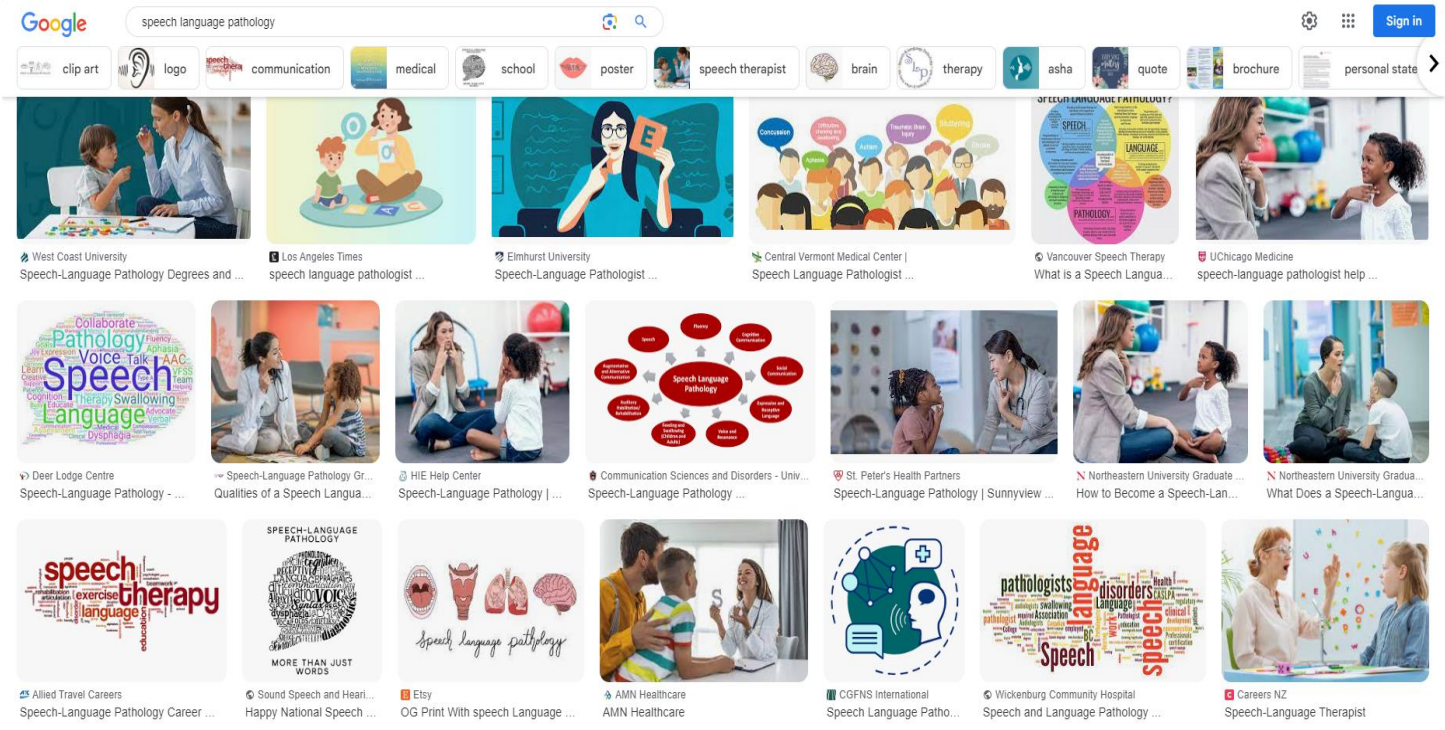
Appendices

Appendix A – Screenshot of Google Search for Speech Therapist



Appendix B - Narrative Interview Schedule of Questions (Family and Community)

For parents:

- Tell me about your family
- Tell me about the journey of getting a diagnosis
- Please share your story about your everyday experiences with your child
- How do you experience having a child with different needs?
- Share your experiences of key events and moments of belonging
- Share your experiences of when you felt marginalised or excluded
- What do you think makes an environment inclusive or exclusive when it comes to children with different needs? and unpack in terms of specific contexts.
- How are you or how were you supported?
- How does this affect or not affect your family dynamic?
- What does your support system look like?
- What would need to change in your community spaces in the long term to create more inclusivity?

For siblings:

- Tell me about yourself
- Tell me about your family
- Tell me about your sibling
- Tell me about your life living with your brother/sister (Did you notice they were different? How did you find out about their diagnosis? What has that been like for you?)
- Tell me about a places you go where you can relax and nobody seems to act different around your family?
- Tell me about places you go where it feels like people stare or don't really know how to act?
- Is there anything that needs to change at shops/parks/malls/beaches and places like that so that your family can have a good time and not worry about what other people are thinking?

For community members:

- You were referred to me by the *name* family. Can you tell me a little bit about your relationship with them? (How did you meet? How long have you known each other for?)
- Can you tell me about your experiences of interacting with children who have disabilities and their families?
- What do you think makes an environment inclusive or exclusive when it comes to children with different needs?
- What role do you think children who have different needs can play in our society at large and within our own communities?

Appendix C - Interview Transcripts

Transcription of Caregiver Interview (Ollie)

Codes	R= Researcher	M= Mother	F= Father
	G = Father's Name	S = Mother's Name	O = The son
	(text)= description	[text] = adds a word in	*Text*= emphasis

Background

I first met O when he was 3 years old for private Speech Therapy. He was largely non speaking and had a few Makaton Signs that he used consistently. S was a frequent visitor to our sessions and the most wonderful active participant alongside their nanny at the time. With communication being as encompassing as it is, S and I developed a very close working relationship and when I was appointed as SLT at the school O attended, our relationship only deepened. There are few bonds stronger than that of being a communication partner for someone with a communication disability and so we came to know each other well as I learnt the intricacies of their family. Indeed, it would have been difficult to know without her that "Bapa" was grandpa, a loving family nickname and an important person in young O's life. S and G provided the colour and clarity of O's life for me to build on.

I have maintained a working relationship with this family since 2016. I saw O for an entire year at which time we worked on articulation, AAC and functional communication, the goals of which were guided by S and G and their vision they had for their son. As we phased out individual sessions, we maintained a relationship through IEDP meetings and car park conversations/catch ups. At the time of this interview, I was not providing Speech Services to O. He is a vivacious, determined and joyful young boy with so much potential. He has come far in his ability to communicate with others and though he still experiences communication breakdowns and requires the input of his family, his perseverance is paying off.

The family was contacted verbally to participate in the study. Once initial consent was obtained, the interview was then scheduled via WhatsApp. The interview took place in person at their home (with mom) and online (with dad at work). O was present in the next room during the interview watching TV and he pops in and out of the interview at various moments. Parents were given a bit more background to the study and the researcher clearly explained the difference in relationship for the purpose of the interview (i.e. Therapist vs Researcher). The interview took place as follows:

M: Hi! (laughs)

R: Thank you so much for making the time to be interviewed. (M: For you anything.). Aw thank you. So just to give you a little bit of background and and it's on your consent forms which we will get to and you guys can have a look at them. But I'm doing my PhD research, I'm here in my capacity as UCT researcher and not Khanyisa employee. (M: OK) So this is a safe space, you could say anything you need about anywhere you want. And so my project is basically looking at how SLT services can be improved because I just feel like working with the population that I work with, that there is more that I can be doing outside of the therapy room than I can inside. (M: OK) Um, so essentially what that would look like is for our kids that use AAC. (M: Mm-hmm.)A lot of the parents biggest fears are no one else will know how to use it. (M: Ah) And should then my role not be teaching other people how to use it? Rather than needing the families to go on that journey alone, OK?

(M: Ok) So personally, if I had a choice in McDonald's, of going to order at the till or using that big electronic board where I don't have to talk to anybody 100% I would use the board every time

[M:100% using the board].Which is in a form of AAC (M: It is). As is WhatsApp, as is e-mail. If there is any way I can not talk to a person, I'm not going to talk to them.

M: I've never thought about AAC like that.

F: Sorry can I jump in? What is AAC?

M: That is that that app I was telling you about from the IEDP. (F: Oh okay)

R: Yeah. So it's Alternative and Augmentative Communication. It's just a very fancy way of saying there are other ways you can communicate outside of speech.

F: OK, cool. I thought so. Just wanted to make sure.

R: Yeah. So that's an example from a speech therapy perspective. So I have a few questions for you. They have very little to do with speech therapy. (M: (laughing) That's OK.) OK but it's more just about you guys and your family and your family dynamic, um, and I just wanna get better insight into what community looks like to you. What inclusivity looks like to you and what belonging looks like to you. (M: Cool.) Amazing. So let's dive straight in. Straightt in. I'm Australian for this one apparently. (M: Laughs)

F: Can we have a different accent for every question.

Everyone: Oooooohhhhh

M: Yes

R: Yes, that's a challenge.

M: No you don't have to.

R: OK, so tell me about your family.

M: Do you want me to do this one or are you gonna do it?

R: Just pretend I don't know you.

F: Go ahead Se, it's all you.

M: So and we have been. (Ollie in the background saying hi)

M: Speaking of which, we have been married 17 years tomorrow. (R: Mmmm! Congratulations.) Thanks. We both forgot about it until the other day ummm (R: Lucky I'm here as a reminder.). Mhhmmm. Thank you. We have Calla who is 11 and was born in 2011 and then we have Ollie, who's 9. He was born in 2013 with Down syndrome and uh he had some birth complications. I don't, do you need to know that?(R: Mhhmmm) OK. So he was born with a Pneumo…Pneumothorax. Is that right? (F: Yeah, that's right.) On his. Right hand side? Left hand side? I can't remember. (F: I wanna say right?) I think it's right hand side and was in in ICU for five days on oxygen and resulting antibiotics and and and but made a quick and full recovery and we were able to leave after Day 6. And then what else do you need to know?

R: What are you guys up to now these days?

M: What do we do? Well, what do we do, G? (laughs)

F: As little as possible.

M: Oh don't talk rubbish. G is an engineer at F. You can see it on his shirt there. (R: Mmhmmm.) Umm and I run my own business as a coach, facilitator and market researcher. And O has been in school for……how many years? 2015? (F: At least 6.) Yeah, 2016. So he's been there. Hmm. C is in grade 6 at V. Hello. One more, one more year, and then high school.

R: Where is she going to high school?

M: If you ask her, she's going to D. If you ask me, I'm not entirely sure yet. (R: (laughs) Ok). OK, we are still wading through what the best options are. Aaaand O does gymnastics. He loves gymnastics. Loves swimming. Calla is all about hockey. (R: Amazing). And not boys. Yet, yet. Hey, babe?

F: It's fine, it can stay like that for now (R: Laughs)

M: Gary's already decided that he will. Do you know that scene in bad boys?

R: Yes, when they go to the front door.

M: Yeah, he's already decided he's gonna do that for her first dates.

R: Ohh. Fantastic.

M: I don't know is there anything else.

R: No, that's perfect.

M: Cool.

R: We'll get to more stuff later.

M:Cool.

R: So tell me a little bit about your journey of getting a diagnosis for Ol.

M: Do you want me to do that one? Or do you wanna do it?

F: Uh, I mean, I'll start and you can jump in. So…The first potential that we heard that there was any issues was at your 21 week scan. Was it? (M: That's Right) No. (M: 20.) Uh… Where we were told there was a, I can't remember the statistic, but I think it was a one in 200% one in 200 times chance that Ollie would have down syndrome. (M: Mhhmmm) And the. The the way in which it was communicated to us was, Misleading at at best, shall we say, especially when you start looking at the the the sort of statistical side of things. I'm sort of fairly practical as as you know. (M: Very pragmatic) And so when you tell me one in 200, I'm like, well, that's still, a fairly small chance. (M: Mmmm.) But medical terms, that's quite a high chance so.

M: High risk, it's a high risk

F: Yeah. Anyway, Long story short.

R: Tell me the long story.

F: Well, I mean from there we will sort of like well, you know there is no point in we're given that this the the choice of you could go and do a a…[M: Amnio] Yeah, that's it. And that's had a higher risk than the risk of him having Down syndrome. So we didn't do anything and there was never any consideration for us to terminate or anything like that. (M: No, no) And that was never, that was never really even an option. And so yeah, we sort of carried on. I remember we sort of prepped the family that they might be issues, but I think. I was more optimistic than Sarah. And she had a sense that something wasn't right. I was like, no, I'll be fine.

M: So this is the optimistic side of the relationship and I am the I wanna say cynical, but not…[R: Realist?] Maybe realist, maybe realist. So can I jump in? (F: Yeah, go for it.) So the the the long. The longer story is. So we had Calla and the pregnancy was absolutely fine. There was no misgivings and all our tests came back fine, long birth with her I think my birth was 24 hours from induction to birth [R: OK]. And and then Oli came and I remember saying to Gary about 3-ish months into the pregnancy that it felt different somehow. But I couldn't put my finger on it. Then we had our twenty-week scan with Doctor Borat who's the specialist. And at that time, it wasn't because we were at high risk at Candace Roberts just sent everybody to him for regular scans and he found a lack of nasal, lack of nasal bone and. There was. There was one other marker. Do you remember what the other marker was? Something about the length of. I don't know if it was the legs or the arms. That bone length

F: I don't remember.

R: OK

M: So that placed us in high-risk um and then like Gary said, he said we could do an amnio to get a, a, a (sigh). What is that a realistic test result? (F: When you get a definitive answer.) Definitive. Thank you. That's the word I'm looking for. But the risk of miscarriage was higher than the risk of him having Down syndrome. So we were like, we're not gonna terminate anyway, so we will just continue on. But I remember going once we booked our bed at Ethekwini. And I remember going to do that. Was it the 4D scan? Were you there for that?(F: I think so?) I can't remember if you were there and and on the 4D scan you could see the very flat facial feature. So I knew at that point Gary is still even today, much more optimistic about life than I am. And so I don't think you saw it then. Hey? (F: I honestly, don't…I don't. Honestly, no. I don't think I did.) No. And then I went into labor. Maybe three or four days before my due, my caesar due date and. He was then obviously born with his pneumothorax and the only got the diagnosis hours after his birth, because the pediatrician was working on saving his life, essentially. (R: Ok) Ummm. And then yeah, we got it in the middle of the night hey? It was a Sunday night.

R: No, better time for a diagnosis.

F: Yeah, that was Sunday, but I don't remember. I don't remember exactly when they told us for sure, you know what I mean? I don't know whether. Yeah. Can't really remember to be honest.

M: I can remember (R: laughs). So. So we – *I* - had an argument with the pediatrician after Ollie was born. As I would. I said to Gary, you go with Ol because we knew his name was gonna be Ollie. [R: Yeah]. Like we had planned that part from the very beginning. And then the doctor said, no, he'll stay with you. And then I said no, he is going with the baby and then we argued backwards and forwards until he put his hand on my shoulder and he was like, no, Gary needs to stay with you and I knew something was wrong.
So you know, they put, they always put the baby with the head next to your head. When I turned, he was purple like you could see he wasn't getting enough oxygen and then they took me to recovery.

Gary stayed with me. And then as we went past the NICU, back into the maternity, where our pediatrician is a massive man, he's huge and I could see him over the bed working on Oli. And that was, I think it was probably about 9:00-ish. And they worked on Ollie for hours. It was only probably about midnight to 1:00 AM the next morning that he came through finally. And he told us that there was a pneumothorax that they'd X-ray, they had tubed him, suctioned him. What else? There was a whole bunch of stuff they'd done. Umm and and and that he looked like he did have Down syndrome, but they took a sample for genetic testing sent it away to Pretoria and we only got that back. Maybe a month later? (F: Yeah, *aaages* later.) And neither of us really wanted to accept it until we got the genetic testing, although it was, it was very clear (R: Yeah). It was very clear. When we look back now.

F: I don't, I don't agree with you. I think I think as soon as as soon as they told us, as soon as Moodley said he has... We both were like OK, he does. I don't. I don't remember going: Ohh no. Let's wait for the genetic test to come back. (M: I do! Not you, me.) I think it was quite…quite clear.

M: No, not not saying you did. You very good at that. You're very pragmatic. It's like, OK, it is what it is (R: Yeah.) I on the other hand, was like, slightly more optimistic and hoping for a negative result. (R: Yeah.)To come back. Yeah, that's. Yeah, we. Well, what what was the original question?

R: No. You answered the original question which was the journey of getting a diagnosis.

M: Ohh. There we go. That's our journey. OK

R: And and when you got the diagnosis, what what was the support like?

M: There was none. There was no support from the medical community. Yeah. So there was no support from the medical community, even pre diagnosis. I remember sitting with the Gynae saying, OK, so because we are pragmatic people, I was like, OK, so we are high risk. What do I need to do to make sure that I give him everything that he needs and the discussion was very much brushed off as in like, Don't, you'll be fine. It will be OK. He won't have it. Like that was the that was the like. Let's be on the optimistic side versus let's face up to reality, you are high risk and the latest research for Down syndrome says XYZ which is. Kind of where I'm at like, that's that's what I want. (R: Yeah) So from the medical community pre, pre the actual diagnosis. There wasn't very much support and then post diagnosis we had a wonderful midwife who was very good but and her name's Desmaya and she was very supportive of us but not very knowledgeable about the diagnosis. (R: OK) Hey? Is that a fair representation?

F: Yeah, I think I think she she was concerned with his general health, which she did a great job at [M: Yes, yeah she was amazing!] but she wasn't, wasn't, wasn't equipped to know information about, you know, what is the Down syndrome society? What support is there? What other things are available to us? She didn't obviously know that. (M: Yeah.) And so that from that side of things, it was very limited.

R: And so how, how did you come upon that knowledge?

M: Um, I'm a, I'm a researcher

F: Have you have you met my wife?

M: I am a researcher by nature and not only in occupation, but like just generally. So umm I didn't even know there was a Down syndrome Association. I have a…vague memory. That they contacted

me from the hospital. I think maybe the hospital sent them my details. And so when Ol was about four months when I could drive again, whenever, however long that is, after a Caesar, I think I took him out to Malvern. And I meet with the lady there who was an older British lady. I think her name was Caroline. It's changed since then and she was semi helpful to be kind. Semi helpful. There's a lot of politics in that space. And everybody was a bit jostly for like I want the Down Syndrome Association to go this way and that way. And so it wasn't super helpful. (R: It wasn't for like the children or…) It it it was. But there was a layer of politics and underneath it. So people pushing for this or that or this campaign or that campaign. And I think being of middle to upper class we are not their target. They are targeting people who don't know anything about Down syndrome and needs. (R: OK.) You know, don't have resources to to do the research so. So there was that then Amy Roger got in contact with me. I think when Ol was maybe [F: He was young, maybe a couple months.]. Yeah, couple months old and she basically said Hi, my name is Amy. I still don't know to this day how she got my number. (R: That was gonna be my next question.) I don't know how I I don't know where she got my number from. And she basically said, can I come over? And she her. She had a little one who was also. Little because I remember her bringing a baby with her and we just chatted through and then um after that, all the research that I did was about early intervention. And and to find therapists who would accept early intervention as a baseline was very difficult. (R: Ok) Everybody wanted to wait until he was about one before they started anything [R: Oh wow.]. Umm. And so it was a. It was hard to find people who would start the intervention earlier than that.

R: So did you find someone?

M: Yes. So we found Di Rothwell. Well, Di Watkins. What's her surname? (R: Watkins.) Watkins. (Now it's Watkins. It was Rothwell.) Yes. And she started working with Ollie from a physio perspective when he was four months, babe?

F: Yeah, there, there abouts. I can't remember exactly.

M: Yeah. So we started with her when he was four months. Uh, no OT would see him until after one. And so we started seeing an OT when he turned one that was Donna Webb. She's been phenomenal. So we've been with her now, actually eight years. When you think about it hey? And then we started seeing you. (R: Yes!) When he was how old? (R: 3? I want to say?) Yeah (R: Yes, 2016 through…) Yeah(R: *Wow*, that's unexpected.) Mm-hmm. Yeah.

R: Wow. OK, that that I'm very surprised by that.

M: Well, well remember. I think it's also nine years ago.

R: Nine years, is not that long ago (laughs)

M: It feels it feels like intervention has become normalized from the very beginning. So and Sam Northend, we had a whole discussion about intervention for Mila and no one believed her that something was wrong with Mila until she got that alternate diagnosis, which only came at four, I think.

R: Yeah and that's hard because there's nothing to measure, and there's no like [M: Yeah] markers to look out for.

M: At least we have the physical genetic markers that can say yes or no. But with autism, there obviously isn't.

R: Interesting

F: I mean, you said you you say it's only nine years ago, but it's it's it's it's been interesting to to see the the rate at which the sort of perception of and how things are done. The rate at which those things have been changing over the last little while, I think they've been quite dramatic you know say you only go back ten years, OK. You go back another 10 years further back and it was even worse.

M: Yeah, put your, basically put your kids in a home

F: So if you look at the the rate at which things are changing and how much more intervention is sort of normalized and accepted and pushed for, yeah, that change in the last couple of years has been a lot.

M: Yeah, yeah.

R: Umm. OK. So the medical professional was not very supportive. And. You found it elsewhere?

M: Mm-hmm.

R: Where else did you find support?

M: So our families were incredible ummm. I think in they were they were incredible in their own way (laughs). So we had some very practical family members who would come and help feed and change so my mom was kind of a little bit like that. And Gary's parents are also very practical. So whatever help we need, we can call on them from a like, a practical point of view, fetching the kids or babysitting the kids, but emotional support….Emotional support? Uh, we lost a few friends. Umm along the way [R: Because you didn't have time they needed, or…]. So I had a very interesting conversation with one of my very closest friends who's lived randomly all over the world, and she don't. I don't think she was here in South Africa when he was born, Lisa?(F: Ok) Do you remember where they were?

F: I think they were still in Brazil.

M: So that I think they were living in Brazil. So what we did was. Because we, because we practical people. And when we got the the high risk diagnosis, we basically just let everybody know because our what my model was. If everybody knows that there's a chance, and when they see them, then no one feels awkward [R: Yeah]. Right? Because then it's like it's out there and and the response on his birth notice was incredible. Everyone was like he was beautiful and congratulations. So that was lovely.

R: But you almost had to prepare people while you were going through it.

M: Oh yes. When we got when we got the diagnosis I phoned my boss. I was working at Unilever at the time. She was incredible. I said this is the case, she said don't come into work. We were having our house renovated so I couldn't go home and so I went to Vicky's house and I lay on her bed and I cried all afternoon. She was so she was amazing. But a lot of people didn't know how to act around us. Now that he was here and. And so this friend of mine. She's she was supportive and lovely all the way through, but only recently did she come. Maybe about a year ago. Did she come to me and say I'm so sorry I couldn't be more supportive. I didn't know what to do for you.

R: OK

M: So we we we had friends that we would see very often and that kind of just phased away. I think actually predominantly a lot of your friends (speaking to Gary (laughs)

F: It's funny. Well, it's it's funny how the that that distance with certain friends happened as he got a bit older. Because when when he was very small, he's just a baby. Baby's a baby [M and R: Yeah].

F: But as he grew up and got older, we noticed there were some people who we would really hear from them less. And you know, I think it had a lot to do with they didn't really know um how to be around and how how to sort of, yeah, interact. Which is, you know, it's sad, but it's one of those things [R: Yeah].

M: Yes, I think that's a very fair representation of what happened. But our church community has been incredibly supportive. So we were at a church in Durban North, and I remember going to church and the grannies, it's always the grannies. We're come and take Ollie. And at the end of the service, you would have to go and search to the church like which Granny has got him now because he would just be passed from person to person to person. D'you remember?(F: Kinda) And then we changed churches to a different church um here in Sunningdale and they were really supportive of us once they got to know us as a family. And as we've journeyed with them. So we've been with them maybe six years now, no longer.(F: Longer.) Eight years, maybe. (F: Yeah.) And they have taken to… like Oli loves to sing. They've given them a broken mike. So at the beginning of every service he goes to where all the mikes are kept. There's a mike that's labeled Ollie, no other children are allowed to touch it, not from our insistence, like, that's not a thing. And he gets his mike. And he gets to walk up and down in front of the service and he sings his songs. And then when people got up to preach, sometimes he goes and stands next to them and and the support we've got is phenomenal.

R: Which church is this?

M: The Rock.

M: And and so we've been very lucky from that perspective. And then we have friends who've journeyed with us. So Ol is a terrible sleeper. You know that, like. And he was exceptionally bad as a baby. So we would have friends who would, like, I could phone and say it's been a a rough night and they would take him for an afternoon. So we could just, like, be normal. (R: OK.) Yeah. So yeah, I think that's a fair representation of everything? I think we've covered everything off? [F: I think so?]Sorry, I didn't hear what you said

R: OK. It's ok, he said you gave good information. Um Ok sooo…I want to know a little bit about how you experienced having a child with different needs and. Kind of what your everyday looks like if you can peg down a routine-ish.

M: We have a fair routine. Do you wanna go? And then I'll go.

F: You know, I mean we we we've, we've kind of you know you you settle into a routine that is normal for for you. You know it's normal for us so there there I'm sure obviously there is a lot of things that we do as parents of a 9 and 11 year old that a a typical family won't do. Um. But, but certainly for us, there's a a fairly normal routine of, you know, in the morning we get up and there's certain things that we do and there's certain things that this kid has to do and this certain things that that kid has to do and. And so from a day-to-day routine it's it's it's it's normal even though it probably isn't. If that makes sense.

R: It's your normal.

M: It's our normal. Yeah. Yeah, I think that's fair. I think that's fair. And your experience?

F: And in terms of?

M: Having Ols

F: Like in terms of day-to-day.

M: No, no having having him with extra needs.

F: You know what it it's. For us, for It's it's like. The the the the challenge is that that is most difficult to. To get around is, you know, with a typical child you kind of know the developmental stages. So you know that when they get, they're gonna get to this little bit. They're gonna go to play school, they're gonna go to preschool. You kind of. There's sort of accepted norms and well known of. So they're gonna develop and and what can be expected. Whereas with Olly. That's, that isn't so much defined. And it's it's.

M: Yeah, that's not defined at all.

F: Well, it's not defined at all. Exactly. There might be some norms, but because they are so small that and your your norm might be different to somebody else. So you you don't. It's very difficult to. I don't know you you obviously the you try not to compare what your kid is doing to the next but it's it's that constant assessing of what does my child need now to suit him best.(M: Yeah.) And and it's that like extra layer of of being cognizant of what you're doing and what needs to be done for him. That's gonna be best for him. Whereas you don't have that, that extra level of thought that needs to go into with the typical child, it just it's almost inherent. You don't have to. You don't have to know what that child within reason there's obviously. (M: Within reason Yeah, yeah.) But it's more obvious we're should all often you like. Kay we've done this intervention for whether it be toileting or, you know, behavioural stuff, whatever happens to be we've tried this is it is it working, is it not working? Should we have tried this? Should we try that and there's a constant like second guessing of of yourself and maybe trying something different so it it feels like there's it's it's like more work. To be honest.

M: Yeah, no, no, 100%. So I would say I, I agree. So we have we have a fair rhythm and routine Monday to Friday with like getting up, breakfast, getting ready for the day. He's got his chores, Calla has got her chores. It's it's a, I would say it's a if I think back to my childhood, it's not very different in terms of the rhythms and routines and expectations and but then you add in the complexity of this like, the constant interventions, because it's not a case of he gains a skill, he keeps a skill. It's like he gains a skill, regresses into in, in another area, or he gains a skill, and then you're like, OK, that's cool. No, it's not concreted. We've gotta carry on doing more work for whatever. Yeah. So from from a normal family there is that like. It's it's not stress as much as it's. Intentionality (F: Awareness.) Yeah, awareness and in in an intentionality around it.Umm but I think my difference to Gary is that my experience of having an even though we're in a a very supportive community, can you hear him laughing in the background? (F: Yeah) And so even though we're in the support of community and we…people can see it right? I still find myself jumping in to either apologize for his bad behavior when he's having a bad day, whereas with Calla, I would never. I'd be like, OK, go and sort yourself out. Yeah. You need to wind your neck in and then behave. Ummm. Or like sometimes communicating for him so people get it because we are part of a community of people who really want to engage with him. So we've also just kind of found I found myself in a bit of a new community now as well, where people are loving him and want to engage with him, and then they'll they'll try and engage with him. But because his um intelligibility of his speech is not that great, they constantly looking to me and I'm like, oh, he says this. Oh, he says that, yeah, this is that. And ohh, this is what he wants. And and when friends' children try and play with them.

Then I I actively have to stand back and allow them to figure it out. OK. Whereas with Calla that was never the case. You know, you they would be in a peer set and the peer set would be at a similar stage of their development and they would sort it out. And if you needed to step in and discipline, you would. But that was quite rare with Ol it's like he doesn't necessarily play with the neurotypical 9 to 10 year olds, he found himself more comfortable with the kind of 4,5,6 year olds OK, but even then you're like. You know, there's always this, like wanting to step into help. Yeah. I don't know.

R: And what has been the outcome when you stepped back?

M: It varies. It varies quite vastly. So there are some children, I think, and I was having a discussion with two moms this morning. They were asking me how cause the they their thought process was. Children can be cruel. How can we stop our children from being cruel to him? So I love that. So now, I was so receptive and and my response was children are only cruel when they come from a background where parents don't show acceptance to diversity whatever that looks like. (R: Yeah.) And so that kind of calmed the situation. Then they're like, well, how do we do it? I said, just let them come. And if they say to me, OK, but what if what if one of the children says what's wrong with you? Then I said we answer the question because that's not being cruel.(R: That's just children's curiosity.) That's a genuine question from a 5 year old, you know. And so it doesn't bother me if a child says that. It bothers me if an adult says it because an adult should know better. So sometimes with those kids, I it's it's it's it's very dependent on his mood. So if he's open and receptive. I don't have to do anything. Here he comes.

Everybody: Ollie

M: If he is grumpy mood, yeah, then I step in. Because I don't want the other child to feel like they've done something wrong and then not engage with him another time then. You know, so that's why, it varies.

Ollie in the background telling his dad he's watching Coco

M: If you want help, can you go and ask Calla please?

Everyone: Bye

R: OK, OK. And. So I'm gonna jump to now what inclusion and belonging looks like for you.

M: Ohh that's a big one.

R: What it looks like for you and what you would want it to look like in an ideal world.

M: Do you wanna go first?

F: No.

M: No? What does inclusion? So what does inclusion currently look like? So again, I think we are very blessed that our Community accepts Ollie for who he is and where he is. So the people close to us, I don't have to apologize for him having a bad day. They know they know the signs, they know the behaviors, and they will. They will discipline and love him the way he needs it. (R: Ok. And who are those people?)

M: So we've got a couple of friends who we see. So one of my friends I see daily and she just loves him. Her name's Allison. She runs the coffee shop that I'm always at. And we were very good friends. Kind of a little bit apart because of life stages, but very good friends with a a family. Who the wife is preschool teacher at Reddham. And she had a little boy who was friends with Ollie who had Down syndrome and so she could then understand from. A higher percent of interaction with people who have extra needs, what we go through in daily basis and they were incredible and he loves them and they love him and their girls love him and that he just assimilates into their family no problem. And then we have other friends who have little kids who are one and three Laiken and Oakley. They love him. And so it's inclusion just looks like being accepted for who he is regardless, right. We all come with bad days and good days and grumpiness and.

F: And some of that, I mean, sorry to jump in, but some of that like that in that inclusion also comes with um constant more consistent interaction, so the the people who we react/interact with more frequently inherently from the outset, probably are more accepting in it and not fussed about things. But but the more you spend time with him, the more they go well, OK, cool. We we know we know Ol. We know what he's like. We're not gonna get fussed by by what he does and who he is and and they just carry on. So it's sort of inclusion, it does come from a you know. A willingness to want to interact (R and M: Yeah, yeah.)

F: And that's sort of where it's sort of starts. And we found that the people who are are willing to do that um then there's no issues about conclusion with them because they've they've taken their first little step of kay we realize there's something different about you, but I'm not fussed by it and I'm just gonna treat you for where I see you. Sorry, I interrupted what you were saying.

M: No, no, that's good.

R: So would I be correct in saying that your version of inclusion is the people immediately around you. Like it's not. It's you. You wouldn't consider it. In like. An inclusive day. If you went to the supermarket, nobody stared at you.

M: No no. That's important. So, so the steering thing used to upset me a lot and and and when you ask me about inclusion, there was one memory that popped up in my head immediately, which was we went down the South Coast. Tooo…Margate, with your parents? No, no, he was he was still in a pram, so he was little and we had stopped at this Banana farm.

R: As you do down the South Coast.

M: Yes. Do you remember this?

F: No, no. I wasn’t sure what story you were talking about, but now I do.

M: And there was this restaurant we were like, OK Calla was probably only three at the time.. max. And Calla couldn’t d long car drives so we stopped, and we had Ol in the pram next to us. And there was a lady who sits just across and. And she just stared him the whole time. But. Obviously, hypervigilant to it because it's been a few months or maybe even a year at that stage because he hadn't yet started walking. And you can tell the the curious stare from the. WTF. What's wrong with you, stare? And that that was a defining moment for me as a mother of a child with extra needs. And I was in my mind. I was like, I can let this go. Or I can get in your face and I can tell you to stop staring. And I did. I literally put my head in front of him and I was like, are you OK? Like, is everything alright?

And she stopped staring um there are days when that still happens and there are days that still, it's still upsets me. But it is again linked. To potentially his behavior. So he has one of his favorite movies, is how to train Your Dragon. And there's a scene where the bad guy, has a staff in his hand and he shot. He's like ahhhh. He doesn't necessarily understand that that's not appropriate to do to other children, and he did it to this poor little tiny Indian child in pick and pay and the mother almost died 1,000,000 deaths.

R: Oh my gosh

M: that I can understand.

R: What do you mean, like, like she was like she whisked her child away?

M: Yes, she was shocked. And then I was like, no, I I would have done exactly like this. Little Boy walks up to my darling child and screams in her face. And I was like, I realized what he was doing, so I had to say to him, OK, we can't act now that's, that's you. You scared the little girl and he was a immediately repentant. But in that moment, it would have been great if post that, the mom had, like, allowed me to speak into it and being like, you know, he has extra needs or so he's not trying to hurt your child or scare your child or whatever.

R: But instead she walked away quickly?

M: She I mean, and and I don't blame her. Honestly. There's no judgment there. From an uneducated space, I might have done the same thing. Yeah, but you know, I would Class a day where we can go into checkers or into a Woolworths. And there is no issues. In saying that, we very rarely have issues, the tellers are always so curious and community…communicative with him. They hi five him, the the security guards at my parents retirement village are so great and they love chatting to him. So even the broader community. I feel like the level of inclusion from 9 years ago is far different. But again it does. It's very dependent on his behaviour. OK, so belonging and inclusion is…

F: Yeah, if if he's if he's in a good mood and in react and and and, you know, happy about going and saying hello to everyone and then then generally the you don't have any issues with really when he's acting out and having a bad day then you find you'll get the stares more so and all that [M: Yeah, 100%.]

R: Ok That makes sense.

M: Yeah, it does.

R: Yeah, it does. Ummm. So you've had very like key memory for you guys and when that exclusion yeah came in where you felt very othered, is there a memory that sticks out in your minds about a time where you were like, you felt like you could exhale like this is…(breathes out).

M: Oh those are daily. Yeah, I mean from the from the microphone, I mean it the microphone at church thing started with a working microphone that was worth like 3 or 4000 rands that our pastor mark would give Ollie because he loves to sing. Eventually we had to say to like, we can't afford to replace that if Ollie just like drops it on the floor. So it's from that to the baristas at our favorite coffee shops uh hugging him, greeting him by name, learning um learning his words for things so that they can understand what he's saying. So for example, the one coffee shop we go to and they do these freezo things. But he doesn't say Freezo, he calls them preezo.

So they know that and then they will come and ask because he constantly asks, he will have one and then ask for another one so they know to come and ask me before they make him one to the other coffee shop that we go to in Florida Road one of the baristas is deaf and she will make her, now, on a busy day or Saturday when we go, she will come to us to greet us and specifically to greet him and and friends, telling us not to apologize for his behavior because they know and love him. I mean. There's there's more inclusion moments than there are feeling othered would you agree?

F: Yeah, I think so. And the the the instances where you've you get you feel the sort of exclusion or othered, however you want to describe it are normally quite fleeting. And normally with people you you just happen to interact with. It's not with your, not with our…

M: Community, yeah. I think also those moments of feeling othered are sometimes self-inflicted.

R: How do you mean?

M: I know. So so Gary brought out this point about not comparing. And so we….Sorry, I'm so sorry.

R: It's so fine. Who are you apologizing to?

M: Your recording. So the moments we sometimes we are in like an environment where there are a lot of children his age who are neurotypical and you realize. One, your level of hypervigilance versus other families or uummmm and and and as much as I love children's questions and parents questions, the moments where there's an influx of them are like, why doesn't he talk? or why does he sound like a baby? or, you know, those questions. Then those moments feel more exclusive, but not from other peoples perspective, it's more of a like a an excuse my language, it's more like oh crap moment. Like OK this is reality because when we in our bubble. We aren't in.We we don't find ourselves firmly entrenched in the special needs community. We are more the unique family in a neurotypical community and loved and respected. But then you'll go to a birthday party and you're like, ohh, right, that that's what normal is. This is not normal. And those moments feel othering than, say, somebody being rude or,nasty. OK, is that a would you is that? Is that more me than you?

F: No, I think that's right. Because you you find that the the instances of someone being rude or nasty are virtually nonexistent. At at most, it's, you know, someone giving you a a funny look or a staring in the in the shopping center, which is really no skin off my nose. I couldn't really care. I've got. I've got past that long ago, but it is more. I think you're right. When you when you go to like a typical party and you sort of you you realize how you do things is different to typical.

M: Oh yeah

F: Which makes you feel othered, but not because of anyone there specifically. Just because the fact that the way you do things is not typical.

M: Yeah.

R: That makes sense. And do you? Do you mind being those people? When they're asking you why he's not talking, why does he sound like a baby? Do you guys mind being those people?

M: No, not at all. I would. I would rather you come and ask me questions than make assumptions. And I'm not. And I'm not a mom. That's gonna be like we'll pick me. I'm gonna go do school talks like one of the people in our distant community is Jess Roberts. She's got a page called learning from learning from Luke. So she does that. And that's wonderful.

I would rather educate people in my community. And it always starts with. Come, come over to our house. Come have coffee with us. Get to know him. That your kids get to know him. That's a better way than doing talks, I think. But no, I don't mind.

F: I think I also like feel very much that if it's that that situation where someone wants to interact and has genuine interest in wanting to interact with with Ollie and with us as a family, that then lends itself to. Sorry, what did he say? Can you? Ohh, no, he said this. Oh cool. And it's that those little interactions and that genuine keenness to interact and wanting to to learn that that makes the difference as opposed to. You know you're not gonna educate anyone else who's not interested, really [R and M: Yeah.].

M: That's true.

R: Ok. So. Ideally. When you're looking at an environment. What do you think makes an environment inclusive or exclusive?

M: Hmm. Are you talking? [R: Bringing out the big guns.]. Yeah. Are you talking at school, community like? Everywhere.

R: Yeah, that I would say with the, with the specific focus on community.

M: Ummm. Hmmmm. Sjoe that's a big question.

F: And again, it doesn't at all boils back down to people really, because I say like the the the environments that you go into are are not gonna be something that makes something inclusive or exclusive explicitly for for us, you know, if you gotta a child who has physical disabilities, then there's there's some very practical physical things that can lead to exclusion and or inclusion.

M: Mmmm

F: But with with Oli, that's not the issue, so it will. It always boils down to people. Umm and environment isn't more or less inclusive based on the environment alone. It's always the people in the environment that will make it more or less inclusive.

M: Yeah

R: Oh Gary, you wise man.

M: He is.

R: Hey?!

M: I would like to [F: Every now and again.]. No, all the time. where I would slightly disagree with Gary on one thing is like one of the places that we feel safe as a family is our church. And it's beautiful and It's cute and because of the people, but there is a level of fear for me there because the the building itself is not necessarily inclusive.

R: How do you mean?

M: OK, so he wonders, he'll just walk. And so for the longest time they had gates open out onto the road. And I would never let him out of my sight, even though there's 250 other adults. I didn't feel like I could trust everybody to keep an eye on him. There's a few people that can handle him. Everybody loves him, but not everybody can handle him, right? And you know, so, so there are certain contexts where I feel safer. So for example, there, there used to be a little coffee garden in Durban north called At TaP. There's a play area. And I loved going there because it was locked. And every mother or parent that walked through the door would always make sure that the only access road. The gate to the road was kept shut. That for me is an inclusive environment where I feel like not only are we accepted, but his safety is also taken to to regard as well. OK, I don't know, am I? Is that fair?

F: Yeah. No, you make you make a point saying that that definitely is. But I whether or not that's. An issue specifically in for us, it feels like an issue because it's been that way for longer, so you know a a normal 2 year old will also wonder and for a for a season. Parents will be half a vigilant of where my child is wandering off to. The difference with Ollie is that season is now been much longer. So it becomes more of an issue because he still wanders off a typical 9 year old. Wouldn't be wondering off anymore.

M: Yeah, but that that does mean that that there is a an environment where it is inclusive like. And I also think about he used to be auditory sensitive. He's not so much anymore, but like going to shopping malls with a loud music and the people. Yeah. And the talking and whatnot, that felt very overwhelming. So an inclusive environment would be somewhere where people would actively not be as loud, but I mean now we talking ideal.

R: No love it, lets talk ideal!

M: I mean, yeah, I think. Am I? You scratching your head?

F: So then you no, I mean it is one of those things that's very difficult to you're never gonna get the the perfect scenario because yes, you you're not not wrong that a shopping center that was a bit more quiet and didn't have the loud music and and overpacked aisles and also full of people would be more inclusive certainly for any child with any sort of auditory processing over stimulation type issues. But in reality.

M: We can’t live there.

F: Is that something practical that you could expect from the world? No.

M: One of our goals for Oli has always been independent living as far as he can. So whatever that level looks like. So it's not necessarily about only taking him into inclusive environments. He needs to operate in the real world, and so we will, we will do what we can to help them operate in the real world. So, yeah, so the wondering is still an issue. It still happens, right?

F: Yeah

M: Like we went up to the African Raptor Centre. At one point I didn't know where he was. He had just wandered off. And and at church, sometimes we still struggle to find him. But that we'll have the ear defenders or we'll make sure we can see him.

R: All of those adaptations to help him cope [M: Yes]. In the environment.

M: We can't. You can't. Realistically you can't expect the world to adapt to his needs. Because the the range of extra needs are so vast. That's some and. And you know that from school Sports day, some sometimes we can clap, sometimes we can't. So we can't. It's it's unfair to expect the entire world to…

F: Not clap.

M: Yeah. Yeah. Thank you. Thanks.

R: Gary! I've got some like golden quotes here.

F: It's just we we expect you all to stop clapping. 40,000 people at Kings Park please stop clapping.

M: Yes, exactly.

R: So thinking about what you said. Do you think that being in South Africa has molded some of you expectations of what reality needs to look like? So I'm thinking about shopping centres in the UK and other parts of the world where they do something called sensory hour. And so there are people that that have extra needs.

M: That would be incredible.

R: They dim the lights, they switch the music off and basically it's like a safe time for those people to come into that space. Do you think that being here reduces your expectation of something like that happening?

M: 100% and and not from.

F: I've never. I've never heard of that before, to be honest. That's the first I've ever heard of something like that. Never heard of that, no.

M: Really you need to join some more groups on Facebook. I think it's not from a community well. Let me take a big step back? It's not from a a lack of desire to want to be inclusive. I think it's an education issue. And I think just based on the vast corruptness of our country and the the lack of basic service delivery that we could never expect that to be a thing. Yeah, I've I've had on numerous occasions with nurses and security guards that I've had to say he has Down syndrome. And they don't understand what that means. Nurses in private hospitals.

F: We've had that in hospitals where they go. Ohh can you tell you can you can you just tell me what you had for lunch? Like? No, no, he has Down syndrome. Ohh, can't he just do this like? No, no he can't.

M: No, not even that! He's non verbal and a nurse will say, OK, what does that mean?

R: OK.

M: So yes, I think to answer your question, living in South Africa definitely tailor's our expectations of what we will get. And again, we are very blessed to be able to be a part of the private medical health system and not a government based medical health system because I am a part of a support group with people who are on that and it's a a very different experience. But no, I don't think we could ever expect anything like that.

F: Yeah, it is very much so that being inside Africa, you you do even this the early basic interventions and whatnot. If you don't have the means to do it on your own it's not gonna happen. You're not gonna. You're not gonna the there's no government structures that are gonna do those things for you. So as say, we're very fortunate that we can do those things. So yes, I agree with Sarah. But but on the opposite side of things. The other thing that, that, that I do think is maybe a positive about South African culture is, there's a lot of, there's a lot of. Willingness to accept, I think.

M: 100%.

F: in, in, in people and and and it's more so in certain cultures than others.

M: Please just be blunt, you can say it.

F: I'll be perfectly I'll be perfectly, but generally the the, the whiter, the white community is the worst 100%, the worst. Every day of the week you'll. Your, your, your, your zulu tellers at the shops and the car guard and the security guards like the most inclusive you you'll ever get. Like always gonna say howzit that they're not fussed that Ollie's different. So inclusive, so, and then there's this, there's a spectrum in between and then inherently I think there's more South African inclusion from people than you might find in. Maybe you're or or or more more western parts of the world. I'm haven't traveled that much, but that's my my gut feeling.

M: Yeah, 100% of. Yeah, that's interesting. Then it might. They might not understand what the diagnosis is or have language for it, but that doesn't stop them from really getting down to his level and like and we've had some beautiful interactions. Yeah, and never with. Some white people.

F: So white people are the worst? Generally, honestly.

M: There's a sense of entitlement with white people.

R: Tell me more about that.

M: No, I mean, it's just I think it's like. It is like this is how life should be and this is what I'm entitled to. And then we come along and we break that mold very clearly because I mean, beyond having a child who has extra needs. We are not. We are loud, we are brash. We are who we are. And so it is like it breaks the mould and people white people don't like it. When you break the mould. Hey? I'm right. Hey?

F: Mostly, I mean, obviously there's there's massive exceptions to the rule, but you know we we we generalize it obviously.

M: Yes, but ohh if we were to put a stereotype to it.

R: Yeah. So then it's like a dark side of education they that they are so aware.

M: Yeah.

R: Like Hyper aware that something is different.

M: Yes!!

R: Like It stops them from like looking past it.

M: And engaging. Right

F: Yeah

M: Yeah.

R: OK. Alrighty, well I'm almost done. Ohh you've been wonderful. The last one is just looking at. Two things. One is. Do you think that having Ol has affected your family dynamic or do you think that it's it's different from how you thought it would be? I mean, obviously you don't have anything to like compare it.

M: No

R: You know what I mean when you have this expectation of family

M: I think it's highlighted a lot. I I don't think I ever had expectations. I don't think I ever had clear expectations of how life would be other than the stereotypical we started dating. We were gonna get married. We're gonna have kids could go to school. Kids would then go to university. Kids would get married. That's. That is the level of expectation I have. I I am never ever wanted to push my children into any one area of life. I think that's dangerous. So. What it has highlighted to me, I'm sorry I'm about to say this, is that Gary's optimism has been highlighted very clearly over the journey

R: by by who?

M: No just because of the way he thinks about how. Like life is good. Like, it's just optimistic about life. OK, I remember having a conversation with him after we received the potential diagnosis. Do you remember this? And he phoned me and at work and he said I think I'm gonna drop us down a medical aid plan. And I was like. Are you insane? We have just been given high risk of having a child with extra needs. And you were like ohh yeah. OK. Yeah, yeah. I didn't think about that. And then you put the phone down. So the that, that level of.

F: And there was more. There was more thought process behind that than than once and puts on but.

M: No, I know there was more thought process behind that. I know, I know. And so that that has been highlighted. But what I can say is I think it's made our marriage and our friendship much stronger. So what I've seen because because of being a coach and because of being a counselor, my church and just a general kind of ear for a lot of people, when people have a child with extra needs, it can either bring your marriage much closer or can take you to the brink of divorce. I don't feel like there's an in between. And I'm not usually a person of extreme. I think we are very intentional about our relationship. We always have been. We've been, I mean, I know I say we've been married, our anniversaries tomorrow. We've been married 17 years, but together 24 [F: 123.]. Not 24, ninety eight. We we got together in 98 and we've always been intentional about it. We we are very good friends. We're very good at communicating when I'm having a low day Gary will step in. He'll do whatever is necessary. When Gary's having a low day I will do the same. It's intentional. so so that I'm grateful for because I think that it's deepened the level of our intimacy in our marriage and. I don't think it's easy for Calla. So we actually we had a discussion last night about chewing noises.

R: Ohh

M: Ollie chews with his mouth open. Yes. Something we've been working on for ages. And Calla made some noises with her. She's just got elastics on her braces [R: I remember that].

M: And she was making weird noises. And I was like, you need to stop making that noise. And she said to me. But you never shouted Ollie, and it doesn't seem fair. So I had luckily been scrolling Facebook and this came up on my feed which says fair Isn't everybody getting the same thing, fair is everybody getting what they need in order to be successful? So we had a great conversation around that. It landed. It took a few attempts, yeah. But I don't think it's easy for her.

R: I mean, that's big in itself for adults to wrap our heads around at the best of times, we're not great at that.

M: Right? Yes! No, no, we not. And so I think for her, I mean, I think. She wouldn't be able to articulate this, but I think seeing Oli go through all the therapies. I think in her very naive and childlike mind toddler mindset that that says that she went through that. I think that's what she thought every kid goes through because she doesn't know what it's like to have in neurotypical brother and. But as they've got older. I see the the strain sometimes that it takes on her and definitely there's definitely strain on us as well. Physically he's been very ill and and out of hospital he doesn't sleep. Behaviourally, they are lots of challenges, so it's not easy, but I think what has highlighted to me is that that need for intentional communication and and being a support system to each other, hey?

F: Yeah, I forgot what the question was, if I'm honest.

R: The question was just around like your family dynamics.

F: OK.

R: Yeah. And how, if Ol has played into what you thought it might look like or?

F: Yeah, I mean it's it's, it's it's it definitely has obviously you know the the dynamic that that our family has. And come to is would be very different if if he didn't have Down syndrome.

M: 100%

F: It…Some things wouldn't be, but some things would be very different. I'm so obviously has has an impact on it and I I mean I do I agree with Sarah, it does it in, in, in any marriage that puts or any family dynamic when there's something that's challenging and or stressful it. It either is gonna be positive or its gonna be disruptive and destructive. And you kind of have to make the choice of how it's gonna be because it is an extra challenge, not the typical child isn't the challenge, but it's. An extra challenge, so you do kind of you see obviously has. Yeah, yeah, definitely has an impact on the family dynamic. But. It's the same as if. Having a having children has impact on family dynamics. And and and kids in generally of of can be very different. So you have one child, you have a have a family dynamic, you have another you all of a sudden. Yeah. Your family dynamic has changed. You have 1/3 at that family are many changes again based on your child's. Characters. Now the fact that all these character requires a little bit extra extra input and has some extra challenges. That that impacts on the dynamic. And so I think that answers the question.

M: So after we painted them in a very negative laps in the interview, I do wanna say that the the way he's positively impacted the family, I think is he's taught us. An empathy and a sensitivity which he picks up on which. I thought I was pretty good at. But watching him interact with people and seeing how he picks up on stuff is next level. So no, we only wanna paint him negatively.

F: No, it's just just by me saying that he has an impact on on, on the way we do things doesn't mean that those impacts are all negative.

M: Yeah, yeah, I I wasn't only saying you, me, me as well.

R: I don't think that you have portayed him negatively and maybe I'm biased because I know how you are as a family, but I I think what he's been able to highlight for you is he struggles that arise from having a child that has different needs, not so much. It's him. It's the way that things are. So I don't think you have painted him in a negative light.

M: Good. I was just thinking like you're like, oh, this challenge and that challenge and hyper vigilance and this and that.

F: Bit tired of his nonsense. Throw him away.

R: I'll take him, just send him home with me. Sarah and Gary, thank you so much for your time. That was really interesting.

M: That was fun!

R: There are things in there that are blowing my mind a little bit. Mainly around like your therapies and like just I have come into this interview thinking of like community as this like big umbrella that we will fall under. But the way that you have described it and being so much about a people rather than a place or anything else has been a good shift. So [M: That's a good recap] thank you for that perspective!

M: Pleasure.

R: And that was wonderful. Yay! We're done. Thank you.

Transcript of Community Interview - Ollie

Codes R= Researcher	A = Interviewee	
(text)= description	[text] = adds a word in	*Text*= emphasis

Background:
A is a small business owner and friend of Oliver's family. She was identified by S and G Rogers as a person who makes them feel included when they are out in the community. A owns and runs a coffee shop called Encourage based in the heart of Durban North. Her shop is rooted in her faith and based on the property of one of Durban's better known churches. I had not met A prior to the interview but I had seen many photos of O drinking a "Peezo" in the middle of the hustle and bustle.

A was contacted telephonically and via WhatsApp to participate in the study. Once initial consent was obtained, the interview was then scheduled via WhatsApp. The interview took place in person at her coffee shop Encourage. As it was the middle of the business day, A was present but occasionally asked to pause the interview to say hello to regular customers and check in on her staff. She was given a bit more background to the study and the researcher clearly explained the purpose of the relationship. The interview took place as follows:

R: So this is the recording, this is the back up plan, I like to be prepared [A: Good Job] Thank you so much. Okay, so Alison, my name is Pri. [Hi Pri]. I got your contact details from the Rogers. And so, I am doing my PhD study currently in speech language therapy, so I studied at the University of Cape Town. And then I did my masters in classroom communication. And then I started working at Khanyisa Developmental Centre where Oli attends. [Yes] And now I'm studying to do my doctorate. [A: It's exciting, man. Wow.] It's very exciting…and terrifying [A: Oh yeah. Well I can imagine.] And so essentially how this project came about is that I worked quite closely with the families that Khanyisa working on their children's language and communication skills. [A:Yes] And what always occurred to me when I was in those meetings with parents is that how so much of the struggle they face is not really within, like my therapy room, it's more at… when they go out. So something that we use quite often in speech therapy is called alternative and augmentative communication. And so it's kids that learn how to communicate with iPads, a bit of a Stephen Hawking vibe, that kind of thing. But a lot of parents, when their kids are so young, are so reluctant to use things like that, because it's not a widely accepted form of communication. It's very other. [A: Yeah] And so that's kind of where I started looking into how practice could maybe be different. Because surely, if my job is working with that child and their family, where am I leaving them once they leave my room, because it's not something that is widely accepted by community. And so I just had this notion of we…that, as a speech therapist, in particular, communication is not just within your tiny little network, it is universal. [A: Ya] And so I started with this notion of community practice and what that could look like. [A: Cool. Very cool] Thank you. I think it's cool, too. And so, my project is basically looking at, um…I want to interview families, I want to find out what their experiences have been in communities. And then I would love them to identify a place where they feel community where they feel included, where they feel like they belong. And so that's how Sarah and I started chatting about you. And so, she has told me about her experiences at Encourage. And as the owner, I just wanted to pick your brain about a few questions about inclusion.

A: Sjoe, I don’t know if I have a lot of answers for that but ask away.

R: Okay, so it is actually the questions I've asked you is more to do about community than it is anything like speech therapy related? And so first of all, tell me a little bit about yourself. Tell me a little bit about Encourage.

A: Yeah, I mean, I think the whole concept around Encourage started a couple of years ago, in New York, my husband and I went over - I was running an NPO at the time called City story. And City Story is all about collaboration. So basically, how do you bring government, church, media. How do those all fit together? And how do we start collaborating better because I think we, we battle to collaborate well together as people. I think it's true, I think, even in a church space, or in a coffee shop space. So everyone kind of holds their own thing, tightly. Even with Khanyisa, everyone, this is kind of like this is my, this is my thing, and I'm going to control it. But if we could just use our talents, etc, and bring it together, we would make so much more of an impact. So I ran a an NPO like that, that was headed up with/by church guys, CEOs, people in governments, etc. And it was quite exciting. And it was a five year process. And we went over to New York with them. But in that time, we were going into coffee shops, and my husband saw coffee shops, and he just wanted to, he was like we should open a coffee shop and I was like, I don't think that's what I really want to do. But anyway, five years later, we had the opportunity to open Encourage and the whole idea. The whole point purpose of Encourage is, every cup comes with a saying. We've got 21 different sayings: Choose hope. Choose joy. You're enough, worthy, all those brave, courageous, every step you take as a victory. It's like they're kind of like we have gotten to a point in our lives where there’s enough naysaying and unkindness around us actually, we just and we just need a little word sometimes, you know, so we just pull a cup and we hope whatever comes, goes to that person and is what they need to hear on that day. [R: I love that] So that was the whole point and purpose to encourage big conversations to happen here. And encouraging conversations and just to be a comfortable and safe space for people where they could just come and chat and get a little word of encouragement. And hopefully they could, like, just change their day. You know? So that's, that's, that's the heart of Encourage is really, just how do we love people? Well. [R: I love that]

A: Yeah, we don't often get it right. But, but I think the truth is, all it does take is just a kind word, or just for someone just to see you, you know, like one of the cups is You Are Seen. And I think, you know, sometimes people do feel like they, they not seen I think so yeah, that's what we've got 21 cups of different sayings. And that's the point of Encourage. And then also, I love gifting. My top one is gifts, and so like meaning like, so like if you’d look at my love languages. If you know me, you will give me something that is meaningful. I doesn’t have to be expensive. Yeah. But like, don't go out and buy me like a chocolate that isn't something I would eat. You know, like that kind of thing. [R: Yes. But I love that.] So I love so we've been looking at more and more gifting and working on like what, like meaningful gifting means. [R: Meaningful gifting.] So you can come in here and you can actually really have a squiz around with a coffee in your hand. And actually find something that someone actually feels appreciated and loved. But you know? Not just arbitrary gifts.

R: That’s so cool. I mean, the most meaningful gifts are the ones where people have bought you something: They say I saw this and I thought of you.

A: 100%. Yeah. So that's kind of what we've done. We also we've got these little keys that we making. So see this key hanging? I've had those done on keyrings like in silver. And we're using words, so like brave, courageous. [R: Oh my goodness] And we've got, I think we looking at Hope, Flourish. And the whole idea behind that key, because they do it overseas at Bethel, but is that you basically buy the key for a friend or yourself. You know, they're struggling with something. And once they have dealt with the thing, once they feel like they've got courage or bravery and felt like they can move on to the next word of the season. Because I'm all about words. So my heart is like, at the beginning of the year, my family and I are always praying for a word and season for us and individually. And as a family what does that look like? So like…One of my kids this year that she felt like her word was joy? And another one was purpose and another… And so like you like what is that word look like for you? And then what is the family word? Like? How do we carry that through the year? Because it's something you always go back to right? So if you're having a bad day, and not being very joyful. You can remember that actually, that's the word. Yeah, you know, but the point is, the key is that you actually give that key to someone that's maybe suffering at the moment or doesn't feel really brave. But you know that they are because it's in them because we all have it in us right? [R:Wow! Allison!] So you give that key to them. And then they okay, they carry the key around with them. And then when they feel like actually, I'm brave, I've got this, you give that key to someone else, Like actually, this is for you. Yeah, that kind of? Yeah. That's kind of that's my, my heart really is. How do we get people to start choosing words of life over themselves, instead of words of death you know. So that's encourage. [R: Beautiful! How do those words come to you?]

A: How did those words come to me? Well, everything that we do at Encourage we, we pray through, so I'm always asking God for wisdom, like one of the words like people are needing to hear, I think for the last two years, we have actually coming we actually coming out of trauma. And ummm and I think that it's been an incredibly traumatic season for every single one of us, including yourself, and whoever, our families. And we, we actually need to start like getting to the point where we start healing again. Because what do is we pick ourselves up, we dust ourselves off, and we pretend like everything is fine, but actually not, we're not fine. And I think that we are in a season now where we've kind of like, pulled ourselves out of a hole and we've kind of stood up and we've kind of dusted ourselves off and we taking the next step forward. But the truth is, we've got a lot of stuff to deal with inside. So that's kind of…so for words at the moment…Like I got a lot of rainbows that came in that I've started buying. Because rainbows for us is a symbol of hope. Yeah. And, you see a rainbow you like…doesn't matter what religion you are. Yeah, there's something beautiful about a rainbow. Yeah. And so I bought rainbows and like I think it's a great little gift to give people like actually hang it in your car, there's always hope. Even in the midst of the storm, there's hope. So, yeah, I just those are the words, I really feel like at the moment that. So the words I feel God putting on my heart for people that's brave. Actually, you are brave, actually, you are courageous. There is hope. There…peace, peace is a huge one that we need to pull out. Because actually, it's a choice every day, whether we choose peace or not.[R: Absolutely]

A: As well as joy, like all of these things are choices. Every moment every morning when you wake up, we actually have a choice to actually be kind, be joyful, be peaceful, we have a choice and we can grab it. One of my favourite things was like listening to this like, like if you think of a storehouse, like so picture a massive storehouse like a Checkers storehouse or Pick n Pay storehouse. It's huge. You've got every kind of product you could think of or imagine. But God's storehouse looks like words, bottles of hope, of love, of kindness, of joy of bravery. So like we can walk into a store into God's storehouse every single day of our life. Because we we can, we can walk in and it's got reams…bottles of stuff. And if you have despair, you can literally replace that bottle of despair. Putting despair here and I'm choosing, I'm choosing courage. So you can take you can take you can take stuff out of the storehouse at any point. [R: But it has to be your conscious decision] But it has to be your choice because the thing is I can choose to be grumpy today. Because the day looks tough or I've just had a mess of a day. Or I can choose to take joy or peace from the storehouse and change that. [R: I love that] So that's the whole thing. Words words words, words, they are so important. We we Yeah. Words are important and choice is important and actually the belief in what that word looks like for the day. Yeah.[R: Okay, that's beautiful. Thank you for sharing.]Pleasure.

R: Okay, so just to pivot a little bit, tell me about…(Interview paused) Okay. So the Rogers sent me here. Can you tell me a little bit about your relationship with them?

A: I've been I've known Sarah and Gary for a couple of years now. We were at one point at the Rock Church with them for a couple of years. And we're no longer there, we're at One Life. But yeah, they just became good friends and of ours, and just absolutely fell in love with O. And I suppose I'm the kind of person that actually just asks the harder questions that some people are a little bit nervous to ask. So what is it like to have a child with Down syndrome? Like It must be flippin hard. And there's, I think that's kind of the first questions I asked and I think Se appreciated actually just being asked those questions because what I've realized is that I can't understand is that you lose friends when you have a child with special needs, because people don't get it. So I'm like, why don't just ask questions. Like I don't get it like O is beautiful, and he is perfect in every way. And like, why do we have to tiptoe around that? Yeah, it looks a little bit different. So like, other day, my son, Matthew, He's nine. He…S was telling him that O will finish school at 14 at Khanyisa and that's when they stop.. And that just drove into conversation that evening with Matthew, because he was like, so then what happens to O after 14? What does he study? What does he do? [R: Yeah, interesting question] So yeah, it was an interesting question. And I think these are the kinds of questions that we need to ask more and more, we need to not be afraid to answer them, when we need to not be afraid of how we ask questions. And also, we also need to get to a point we don't call them them. And they and those children.

R: And those children. Yes I'm sure you saw the video!

A: I'm not 100% sure what those children are, but I know that Oli who he has special needs is an incredible boy, he is perfectly made, you know, but it is hard. It is hard to have a child with special needs. Because it comes with a whole lot of fun things.

R: And how did you answer your son, Matthew?

A: So I said Matthew, the exciting thing is is that O can doesn't actually need to study anything. God has put whatever he needs inside of him. So I was like, he could work as a packer at pick and pay. We could have him working at the coffee shop, he could be a barista. And I said actually they have homes, like they're adapted homes, where you actually have someone caring for you. But you can get married one day and you can be in a house. And I don't think it really simply answered his question because he's still in the concept. But now you finished school, he's probably thinking to himself, shucks, I wish I was O right now. But yeah, that's kind of how, but he was like, I don't I don't get it. But I think those are the kind of things that we just need to be more real with people. Yeah, we need to be more honest, be more supportive. Like, like I said to S, in one of our first conversations, I said, the reality is, is that when we pregnant, the first thing we pray for, or we hope for you wish for is that that child is 100% perfect in what we think is perfect. You know, 10 fingers, 10 toes, no disabilities. The big Down syndrome, you don't want to hear that that is not the word you want to hear. You know, there's nuchal fold is a little bit thicker than normal, you know, like, those are the things we do not want to hear. And then you you hear it? And then you like, what does that look like? Because Sarah and Gary's life looks completely different from my life. And my children, you know. And so we need to be supportive, we need to be understanding, and we need to love them even more than you love others. You know, that's my feeling. And so yeah, we allow O to sit in the middle of our coffee shop, on his iPad [R: On the floor. Cross legged.] It's an absolutely incredible skill the way he sits, if I can be honest. Honestly we all need those kind of skills, you know what I'm saying? Yeah, and he sits at the back and my staff know that he wants a Peezo and the Peezo is a freezo. And we know, you know, and like actually, when he asked for this, just make sure S has said yes to that, as well as the next next because that is a staple. But that's the only way we can be accepting and loving of people is just to be a little kinder. And actually, I think kindness does mean asking hard questions.

R: And where did where did that philosophy come from? And you being able to ask those hard questions or wanting to ask those hard questions.

A: I think at the end of the day, my precedent is all about truth. And I want information. So I think for me, it was a personality thing. I'm like, Okay, let's just cut the rubbish here like honestly, this must be hard. So tell me, what is it like? And then you like realise that people are too scared to ask questions. So they just kind of like step away from the situation. [R: Yeah] And then that's like, well, we don't really want to bring him to the house, because we don't want him to disrupt or it's difficult to go to a coffee shop because you don't want to disrupt and I'm like, disrupt! But that's me. And so like one of his friends I don't know. I don't think he goes to Khanyisa but one of his friends have a little playdate here like once a month or whatever. And his little friend was like, but O is going to be here. And O wasn't here, the mom had brought him just to be like, she wanted to show her mom the coffee shop actually. And he arrived, and as he walked up the stairs, he was like O! Like screaming O! And she's like O is not here. And I watched her feel completely rattled and all I wanted to be was like let him scream O for the next half an hour. But she was like "I'm gonna go". And I felt that's so sad. Like we've all had a child that's had a tantrum on the floor let's be honest. Like sitting in the middle of Pick n Pay and tantrumming. [R: I know you want the chocolate, you can't have it] You can't have the flaming chocolate. But it is different when you have a child with special needs because it makes people look slightly differently at you. So yeah.

[R: Yeah] I just like to ask questions because I just feel like the more information we have at hand, the more we can understand their situation and I'm never gonna get it right. I'm never gonna get O right. And I'm never gonna get S and G, like, you know, there are times where I probably asked a question where I should have, if she didn't love me as much as she did, she probably would have been like, actually can't believe you asked me that question. But, but I think I think more and more people need to be told, actually how to act around people with children with special needs. [R: Mmmm. Absolutely!] And what not to freakin say. And that's why I loved her video because it was brave. [R: It was so brave!] And it was courageous of her to do it. And to be honest, you shouldn't have to. But anyway, unfortunately, we have got to that age, where we have to. Like, honestly, we also know the heart of the person that did it. Love those children. Like it's really sweet of you. I understand you love, the fact is let's change the way we speak about anyway. So I've tried to make it as inclusive for anyone like I would for anyone Encourage is all about everyone's included and everyone's welcome. And O just adds a cool little vibe to it.

R: He's got a lot of spunk that kid.

A: That kid's got a lot of spunk. And also, I'm not afraid to tune him back. No, like when he's sittng there and tunes me "no". I'm like "you don't tell me no". I'm like "no yourself". Because the reality is he is he's normal. He's a normal child in my…for me, he's a child is beautiful. And I will do the same thing to my child. I'm not going to treat them any differently, because he looks slightly different. Or. You know? [R: Yeah, do…what…was it a period of adjustment for you from when you first met them to what your relationship looks like now?] I think in the beginning, you always kind of like a little bit more super sensitive to a child with special needs, how they're going to react to whatever. But now I treat every child exactly the same as I treat O. Because like, honestly, he still needs boundaries. He still needs firmness. I don't feel sorry for O one bit. Yeah, like I have moments where I look at S and G and think flip it. Like I don't feel sorry for them. It's like shucks you are so brave. [R: Yeah] It's so flippin hard. Yeah, your life has changed completely. They don't just go away for like, a weekend at a time. Do you know what I'm saying like, it's not like, oh, we can just leave Ol and we can just go away for like an entire week just by the by ourselves. That isn't their lives. It's not a portion. And that is hard. Yeah.

R: I think they they, as a family appreciate the empathy rather than the pity. [A: 100%] Which I think is probably what's so special about your relationship.

A: Totally, I'm like can you imagine not being able to go away? Like on a weekend, like it's your wedding anniversary or whatever? No way, but now we must freakin…(gestures) because there's no way to, for someone to look after him. Can they actually do a good enough job? And also the reality is he doesn't sleep at night too. So then it becomes like a problem.

R: Yeah, I hear you. Okay. And A tell me have you? Have you known anyone? In…throughout your life with a disability?

A: There was a little guy that he wasn't little actually, I think he was like, 25 or something. But his mom and dad, he was he had Down syndrome. And he lived with his mom and dad. In the area I used to live in, and he used to come and chat with us when we were kids. And I remember as a kid being quite like nervous because you're like what is this, what am I gonna do? But once again, it's all about information. So that's the only person that I really knew with special needs. And then we've got those two phenomenal swimmers. Have you met them? Dunno if you…? [R: I haven't] And if you have they are Olympic swimmers with special needs. I think they're married. [R: I love it, I love a power couple.] At like, for sure!! And I think he like was a till packer at Spar. And he's just honestly, just they're both like, brilliant. And I think they live in an adaptive home etc. Yeah

R: Amazing. So, earlier, when you were describing, encourage you said you wanted it to be a safe space. [A: Yeah.] What do you think makes a space safe or inclusive?

A: I think I think allowing people just to be and, and to I think a safe space actually is um…asking the hard questions. I think that actually creates a safe space, believe it or not. And I think the safe space with S is knowing that actually everyone's got an O when he's here. And it's not just all on her. You know, so like he'll sit at the back on the iPad. Sometimes. Not all the time. I mean, we don't use an iPad all the time. But he'll sit there and he knows, she knows that like my baristas they love him, they've got him, you know? And that wasn't anything. Like we didn't they didn't actually have to ask any questions. Yeah, they were just like, like the other day. Like Oli's gone, Philani is gone. He's like, Ollie asked me to take him to the bathroom so I took him to the bathroom. So that's okay. Because he didn't do anything. He just went. I was like, so I think that's inclusivity you know, yeah, it's just like. No one's rolling their eyes, no one's staring. [R: Difficult to control when you have like patrons and stuff. That's not…You obviously can't control everybody that comes through the door.] No you can't control it. But I reckon it is a few safe places, spaces around you. So people around you don't worry about the one or two that might not be the safe space. But I think the more and more I watch people with O, the more you realise that actually people actually are trying to make a difference and be inclusive. And actually they do look at O and they love him.

R: And what are those interactions like when you're watching from afar?

A: Yeah, so we've got a few ladies. So there's a few like regulars and so they all know O and so like when they see him, O walks up the stairs and everyone is like "O!!!!!". And he knows pretty much everyone's names, and he'll give them a hug or whatever. And they'll ask him questions, and then they'll try to speak to him, or whatever will make effort even when he like palms you off. You know, like when he's had a bad day. [R: Yes.] And they know that there's a few people that are on the property regular, they're just really just actually include O in everything you know? Which is cool. So got a lot of kids coming onto the property as well, often Northwood after school and all that. And they have made friends with O and say hi to O and maybe because we in more like a church environment its a little bit easier. [R: How so?] I suppose people on a church property are a little bit more filled with grace, a little bit more filled with love and maybe a little bit more like "ethically" correct. If I'm saying saying it's like, you know, maybe what they saying…what they feeling inside, they're not saying outside. I'm just joking.

But, but I think that's like, I think we've learned that this just a little bit more inclusivity like I think The Rock (Church) where they have been amazing with O. [R: Yes, Sarah mentioned. He's got his microphone.] He's got a microphone, and we all taking pictures of him while he's on the microphone. Because a its so friggin cute. And I've seen that moments of pure beauty with O. Like, he standing in church and there's lady crying, and he'll just walk up to her and hold her hand.

R: You know, we had that exact discussion, O, when he comes to you. He just knows, like, most days, he greets me with a hug. But on a day, where I haven't said a single thing to him, but maybe I'm having a more difficult morning, he'll come with an extra like, little tap on the back. [A: Yes, the tap tap] R: The tap, tap, tap. I'm just like How did you know? And I'm, I'm just infinitely better for it. [Allison: You know, they know, he knows. It's like intrinsically he knows, it's just like human nature. Anyway…]

R: Absolutely. Okay. And then in terms of like your baristas and the way they interact with O, how, how does that inclusion from you filter down into your staff?

A: I don't think I've done anything. I just think that they are nice people to be notice. I think though, like if you've got someone in your space, and you're not hacking and worrying about them, or like telling them to get out the way or like getting irritated with the little kid that's in the middle of your passage. I think they feel that you're comfortable with that they're comfortable with that, you know, but I mean, they my f…they friends, they not just my staff. Like, obviously they are staff and if there's like a problem, we can chat through the problem. But they are good people. I really don't think it's anything that I've done to be honest with you. I think it's just that they're nice people. Okay. [R: I love that. I think you've…you seem like you're very good at discerning character. I feel like you have made wonderful choices that make people feel very welcomed.] Oh, thanks, man [R: In the short time that I've known you] Oh thank you, we friends you and I. Yeah. But I mean, that's. Yeah, if we can just make life a little bit easier for those who are like struggling a little harder.

R: Yeah, absolutely.

A: It's cool.

R: Okay, and then this is more. A little bit more out there. What do you think? What role do you think that children who have different needs can play in our society at large in the world in general, and within our own small communities?

A: Yeah, I think that we need to have more like adapted spaces like to a friend of mine, she's also called Allison. Her daughter is 19 or 20 now. Abs….Casey (KK) she brings absolute joy when she walks into a space, but she's an encourager. She's like, honestly, she like walks up the stairs. And she's like, 'A you're looking so pretty today, I love your dress, like I love your top', if we can find where their gift set is. Because every child has a gift set, it's like what is your gift set or whatever. So O has a gift set, R has a gift set, I have a gift set. Everyone's got something that they carrying, if we can tap into that, and we can use them. So like, um, so KK, she's an encourager, she would be wonderful…I actually had a conversation with Allison other days, like, how do we incorporate KK into a space like this?

Like maybe once a week, so she feels that she's making money on her own, and she's independent, but it's also safe. But she would encourage you when they walked in here, literally would know the names be like life you're so beautiful. I love your eyes. Your eyes are just so beautiful. They sparkle. Yeah, she's that. Yeah. And she's just amazing. So like, I think it's important to try and like be be intentional. What is the gift set? I wouldn't put O in front of house. You know, like, at the moment, that's not his gift set. But maybe it would be a great barista behind the counter. And he'll make a great peezo one day. Maybe, maybe that's what it is. Maybe he'll make a great egg and bacon roll. He's got something in him. We just need to find out what it is. Maybe he'll be sitting on worship, leading worship. He feels the holy spirit more than I think majority of us. And, and so I think for me, how do you incorporate a person with special needs. You find their gift set you you use it to their ability. If that means that they're great at packing stuff, put them on till packing. You know. If they, if they are welcoming and encouraging and loving, put them in front of house. Don't give them anything that's going to be overcomplicated. All she is hired to do is greet people and make them feel loved. And you've only got a 30 second time cap with each one of them. You cannot spend time with them for more than 30 seconds. The next minute KK is talking for 5 hours and the person thinks I'm never going back there again. She is lovely but…There is a place for everyone.

R: And how do you think? How do you think we can get establishments to come on board? With creating things like that? Like how do you think we can think outside the box a little bit? I mean…

A: Like in America, you I don't know if you've seen this space America where they have a coffee shop for children with Down syndrome? [R: Yeah] I think we can find spaces where you can create something like that. So that's a little bit like every city has a few spaces like that, that someone with a heart for that is leading and running. And the other thing is like Spar have used as packers. So if we were more intentional about it and actually went and spoke to the CEOs of SPAR and said to them: Listen, can we incorporate one special needs child. They they're not going to have a tantrum. This is where they are. They're old enough, mature enough to do this. They've learned this dah dah dah. Can we? This is what a safe space looks like for them. They can't do this. They can't do more than that. Can we use him as a packer? Maybe they can just pack the groceries? Can we be inclusive with them, and then partner with him with someone at the till that can help them. But you can have big conversations. I just don't think anyone's ever tried to go and have like a big conversation with people. Yeah? [R: Yeah, I know] So yes. So you go to the big guys. You go the CEO of Spar and you go to the CEO pf Pick n Pay and you go to the CEO of Woolworths. And then you go to different people, you'd be like, because guaranteed one of them has a family member that has some type of special needs.

R
How do you access them?

A: You find someone that has access to them. And it's easy for me to say because I have access to people that because of where I worked with City Story. It's I feel like it's easy, but I honestly believe that the doors can be opened because it's always a conversation, right? For you to stand up and talk about this in front of someone.

We would love to talk to someone to Pick n Pay or Spar or a small business or duh duh duh duh to get them into employ one one special needs child per Pick n Pay around the country or whatever or Checkers or whatever. Or someone in their group is going to know someone. Do you know what I'm saying? [R: I know what you're saying]

If we don't have conversations, that doesn't happen and if we don't try knock on doors they're never gonna open. Not magically opened. But it has to be strategic and it has to be cleverly thought of. So what does it look like? Okay, I'm going to put a proposal together okay. We propose that this is what it looks like, X amount of money that they tell you that they get they only work half day. Yeah, and there's like, I don't know just gives hope. I mean, I'm talking big pictures [R: Yeah. But no, I love big picture] You know, like, like Ames? Like she has people she can access. Businessmen! [R: Yes, she does and she has.] She has accessed them well, but you can access them for anything. So I really do believe that God has placed various things in different things. And she certainly might not have...She could access people. We've all got someone at some point in some way in our scope, where they can access someone. [R: Someone in our bubble] We just have to have a really clever strategy around it. So it's not just like, so like I've started the conversation, this is what I feel you should do. Someone needs to put it onto paper. That is not my vie. No, but that's the point. Right? What does it look like? And I think is a space for children, not for everyone, because you got to be realistic, that not every special child's…special needs child is going to be able to even cope for an hour somewhere. Yeah, some of them.

R:Yeah. That's the truth.

A: That's, um, that is, unfortunately the truth. But out of 50% of kids that go to Khanyisa. Yeah, some of those. Some of those guys could do a sterling job somewhere.

R: Absolutely. 100%. Okay. And then, just in terms of, so you spoken about America and your experiences of what you've seen there. We had a little girl that was at Khanyisa. And, and her parents, well, they as a family immigrated to the UK. So she's got autism. And S and I even spoke about her that difference between invisible disability versus seen disability, it's obviously quite a different strategy. And they're one of the families that comes to mind, often because they were the ones where she was having a meltdown in a supermarket. And it would just be judgement, because they don't, she looks so normal, she looks 100%. Like, anybody on the street
[A: But nobody knows that she has autism.] Nobody knows she's got autism. And so something that they really valued was recognition for her and for their family. So she didn't feel like the mum didn't feel like they were going to get that. And so they emigrated to the UK. And in my catch ups with her, she just mentioned how they have these lanyards for hidden disability. So whether that is autism, whether it's anxiety, whether it's seizures, not something you can outwardly see, but you've got this for you. [A: And then people know that people know what that looks like] And then people know that people know what that looks like. So when there is a meltdown at the supermarket. [A: A good one would be for Aspergers too, because what happens is they come across like completely rude. And it's true like, we don't want anything to do with you, you're such a rude person.] R: And how would you find employment? How would that like…

A: Yeah, yeah yeah. Super incredibly bright. You know?

R: Very capable, but just maybe not having those social skills.

A: Absolute chop sometimes. They just come across as like mean! [R: Yeah. Yeah, yes, absolutely.] I love the lanyard idea. I think it's fantastic, especially for the hidden, because obviously, you look at Ollie and you know exactly like O's got Down syndrome.

R: So I just I find it so interesting, those those parallels between what you're saying what your experiences overseas, and to where we are now, South Africa, as a country. What do you think…

A: Well think about culturally what it looks like and cultural [R: Exactly!] I the rural spaces, a child with down syndrome or even albinism and what effect they are literally seen as like, the lower class. They did not to have the love and the care that is needed. O's life is completely different from the child is sitting in a rural space - completely different. That mothers on her own. I mean if S and G feel alone. I can't imagine what it feels like for a child in a rural space. So there's a much bigger picture and a much bigger conversation to be had across the board. How do we love everyone in every area? Well, because South Africa is a bit of a tricky one. [R: It is hey]. It's very tricky. Yes you have poor M in England or whatever, but. You've got things in place. Like G and S are on the highest medical aid you can get for O, highest. A child that is sitting in the rural space has no medical aid at all. They don't know if neurologically he's degressing (regressing) or if he's got a ear, nose and throat problem because the truth with a person like a child like O is like underlying there's so many things that could go wrong. Stomach problems. [R: Yeah] It's like so scary. But I mean, that's we I digress. But I'm like…[R: No, that's exactly where I wanted to go]

A: It's a much bigger picture. It's like its a much bigger conversation as opposed to like more of your wealthy families. They're not wealthy. But more of your families who can afford a high medical aid, as opposed to the families that cannot afford medical aid or even have access to anything. So how do we tap into that market. How do we tap there? It's not a market. This is a marketers talk. How do you tap into that? [R: Yes yes, exactly! How do you tap into that community?] That's not a market. How do you tap into that community? Because I watch S and G and their struggles, like something goes wrong in their family, like just G's mom being sick. Next minute, O is like all fall down. I don't understand that, you know, because, you know, like, a child without special needs, they have their stuff, but a teenage daughter can have their stuff but at least you can have a proper conversation with them to help them to self-regulate. Yeah. Whereas you can't with O? [R: I love that word - self regulate] We all need to self regulate. [R: We all need to self regulate. Just give me a hug or deep pressure.] Some people need touch or some people don't and some people just need a coffee to self regulate. [R: Exactly.] But I think that is the question. I think those are the questions that should be also being asked, like, you know, more and more stuff on Instagram is happening at the moment as well, like, you look at that little girl that has Down syndrome that has, she got like so many followers, she's actually amazing. I think she's in North America, but she does gymnastics, and all that kind of thing. She's blowing it out the water. She's absolutely phenomenal. And the parents have helped her to do that. So there's so many stories of her but more and more people can get onto it. I think we need more and more stories of hope. More and more big conversations. More videos online. And I love the fact that you in England and America, they starting to bridge that gap, you know, like a child with Down syndrome, you know, something that looks a little bit different.

Maybe they need to focus on the autism and aspergers actually the child looks perfectly normal and inside is dealing with this. This isn't this I think knowledge is key. I think we've been I don't think we've we've really tapped into the market of giving people the right kind of knowledge. Because people are too scared to ask questions. Straight.

R: Yeah, it is the truth.

A: And if you haven't, if it hasn't crossed your path, you don't really care. It's cold. Yeah, but that's people

R: How do we make people brave to ask those questions?

A: I think it's like, one line is 'don't be afraid to ask people questions' because actually people need. Like it was a need for S. She needed to be answers questions and actually made me feel like someone cared you know? So through your research career. You need to think of marketing, clever marketing strategy of what are those what do those one liners look like?

R: Yeah, we actually we made at one of our last market days we made these badges that was asked they were ask me about for your handbag for your jacket. Ask me about Down syndrome ask me about cerebral palsy ask me about autism.

A: Oh that's clever

R: Stick it on your car keys or wherever

Allison: And then people would (nodding)

R: And then it gives people this big like ASK ME. I'm not afraid just asked me.

A: But then you need to be vulnerable, right? [R: Absolutely!] So people are too scared to be vulnerable. So one of our stickers is vulnerable is brave. But the truth is, that like I might have been brave enough to ask Sarah those questions. But there's certain questions perhaps I'm sitting with someone now it becomes like a vulnerable moment. She doesn't really want to hear the answer to it. Sitting with your, I don't know, boyfriend or fiance or whatever that looks like and now you have to ask your vulnerable question that you're a little bit too scared to ask because what happens if that is an answer I do not want to hear. [R: Exactly] Don't we all, all of us. Even with like parents, family or whatever. So like, maybe that is. Like maybe to take it vulnerable is brave. Ask questions.

R: Yeah. I love that. Vulnerable is brave. I love that.

A: Cause it is brave. Yeah, it's the bravest thing you'll do is to ask hard, real questions.

R: Can I ask if you'd be willing to share any of the hard real questions you had to ask S if you remember?

A: Shucks, that was so long ago

R: It's been a long time

A: So I do remember saying that it must be really hard for you when you find out. Like. How are you doing? You know, like, I was like, I think I even got to the point where it was like every parent prays to not have a child with special needs. [R: Okay. Allison!] It's the truth. Yeah. Like it's not like we do not sit there and be like my child's got down syndrome. [R: It's like a taboo truth to like, nobody wants to admit that that's the thing.] Nobody wants a child with special needs. [R: Yeah. But then when you say it.] But then you say it. But then you learn like, O is perfectly intrinsically beautifully made. We would not want to do life without O as hard as it is. You know? [R: Yeah, I know.] Like, so I'm always like, so I've always been if I fall pregnant with a child with special needs that is not for me, I wouldn't ever abort a child. But if you speak to a child, of a parent that has a child with special needs, and you say, what would you do now? We want this child more than anything, but it would be a tough one to do it again. It's an interesting scenario. So those are the kinds of questions I have. And I think it was a it wasn't like fun… I don't think I think but I think if you know, I literally just am like. It's hard. Yeah, it must suck. Yeah, it does suck. Like when she's awake. I mean, when they've had three nights in a row of sleep, it's like a a win, I'm like Yoh! [R: Yeah like you've slept past 3am!] It's like we've had three naps, we have slept the whole night through he hasn't woken up! It's a killer man. Put exhaustion on top of everything else, and managing his feelings and emotions as well as yours, because that is what they do on a day to day basis, they have to manage O's feelings. And they have to manage C's (O's sisters) feelings, as well as manage their own feelings. Freaking hard. [R: So friggin hard.] And that's why people need to love them. And so that's why you want safe spaces, you want your house to be a safe space. You want them in your house, I don't care if they break stuff or scream or the TV is blaring, because they want to watch a TV or whatever that looks like we have to create spaces for our friends, like we do for any other friend of ours. We need to create safe spaces for people.

R: And do you think that is also a little bit of our job, obviously in conjunction with the families, because we are their community, that we need to be looking at, like creating new normals and more about into what that looks like. So someone, like say for example for O, you're just like, not knowing their family at all. You walk in here, and you're like, oh, gosh, they have a child with with special needs. That must be so difficult, without knowing that O can do this and O can do that. And O loves this. And O loves that. For me, the way that we're always measuring our kids at Khanyisa is against a neurodevelopmental society, like a neurotypical society. So we're always like, what job can they have within the society that already exists? We're trying to fit them into, like these, these avenues where we know what it is. And it's typical. It's developmental, even when we're looking at kids in our milestones of reading, writing, that kind of thing. There have been kids that have autism that have learned how to read and write at 21. And not at seven, eight. Do you think that it's also part of our responsibility as their community to not not take that on but to support them? When they're saying, This is my son, he doesn't necessarily fit into a box that we currently have. But maybe we can build a box?

A: Yeah, I think it's, I think, in truth your children do not even have to have down syndrome or, or any kind of special needs for us to create spaces like that. That is the truth. Just because you don't have a tag to your name or look different or whatever doesn't mean that you don't need a separate box.

R: Yeah. Do you feel pressure as a parent that your child needs to fit in a box?

A: No. No. Noooooooooo. [R: Love that!] No, I think that as I've grown, yes there are certain things you have to do to take part in. So yes, you have to do school and you have to pass it. It's for me, it's like that, because it teaches you so much more, sports is important to do because it teaches you how to collaborate and to be with people and to actually work as a team. For sports I'm talking about like for my children actually, like my son Matthew has ADHD. He's at Livingston at the moment he will come back into Chelsea next year. So he's been, he left, Chelsea went to Livingston, and he's still been doing sports at Chelsea. So Matthew fits into the good little sportsman box. When it comes to reading and writing all that kind of thing, not Matthew's strong point, never going to be Matthew's strong point that is reality for us. He will but he's got a great little mind. The box of school for him it does not fit for him. But the sport at school fits incredibly well for him. So we've taken him from Livingston, we put it back in Chelsea, we know he's gonna struggle we tell him it's okay, that it's gonna be a little bit harder. We tell him we're gonna be there for him when you're going to be there. But enjoy life, what is good for you. But you still have to finish school. So we're gonna, we're going to tick those boxes. [R: And that journey for you guys moving him from Chelsea to Livingston….] A: Yeah, it was hard. And this is the thing I said to S like, it's so interesting because I'm sitting across from a mother that has this child that ticks none of the boxes that that can't necessarily at the moment. Sometimes he has a good month, sometimes he has a bad month and he like he gets there and now he's being told no something's… is freaking tough. So she looks at me and my concerns with Matthew. And I'm like, they are nothing compared to your concerns yet, but they're still very real concerns to me. [R: Absolutely] And I don't want him to feel less than, that's the whole stupidity of boxing, I suppose. It's because I don't make it. But the reality is, if you don't fit into that, that thing, then they feel less than and then everything gets knocked along the way. I'm not good enough. [R: Yeah] It's a mess. People put them in boxes anyway, even if you don't care about the box. But I think we can create specific boxes for people. We just have to strategize. And we have to get people's heads together and say right, how does this work? But you have to do it together. The truth is, no one can make these decisions on their own. You have to have a group of people that are conversationing and having like workshopping. What does it look like? Let's have some real hard questions you know? Your life doesn't look like this compared to my life. My children will hopefully one day leave the house and be happy. Your situation looks slightly different. You will always need to worry about Ollie, maybe he'll be on an adaptive home. But the reality is you still going to be taking care of Ollie. That's the box for Ollie an adaptive house is another box but I mean, it's safe place, whatever, then maybe he'll find the most beautiful woman…all those difficult things.

R: Yeah. And even I'm sure even with your son, you want the whole shebang for him in life.

A: Totally. No one wants their child to struggle. That's the truth. Like it would be great if Matthew didn't struggle with reading and writing, you know?

R: And are you open to adaptations for him? Like, with the way technology is developing? There's all sorts of like, supports for people who don't love reading or writing?

A: Oh like tell me about the supports, like on…

R: Yeah, like on like, on a laptop or whatever, like, so even on an iPad, they have an accessibility function where it basically if you had to go you can use like a speech to text and ask. And then also, once you've reached the Google page it reads out the Google page to you.

A: No I have no problems with that kind of thing. They live in the day and age of those flaming iPads and everything else. Yeah. Yeah. A couple of years ago, we were told that Matthew had to go onto Ritalin. That I did not love that. I don't love the idea of Ritalin, I don't love the way it makes him feel. We put it on, we put him on it. [R: Yeah?] But we do not do weekends with it on. And I do not do holidays with Ritalin either. But I wouldn't call him like, I think he just needs more of it for school so that he's more focused. But he's not like completely, like over the top in the week, I think because he plays so much support. He's really got all that energy out. But Ritalin is so difficult one for me. [R: In what way? Just that he…] Just because like the lack of eating and the way it makes him feel and yeah. We use it. I just don't love it. Does that make sense?

R
Yeah. And so when he was diagnosed, and you had, he had that option of go onto Ritalin,

Allison
It took me a while to decide whether we're going to do it or not.

R
Okay. And were the doctors supportive of your decision at the time that you were taking or they were just like, this was the only option that…

Allison
Livingston is supportive of that because I think it's their idea. They're a great school, but the idea is, you take Ritalin in order to help you to concentrate on your schoolwork - done. Don't come here without the ritalin. You know? And they're very clear on that. So, if Matthew hasn't taken one of his medications, there's also there's varying degrees of teachers. One teacher was super savvy. If he had forgotten to take it one day with by 11 o'clock she had messaged and be like, did Matthew remember to take his medication this morning?

R: Okay. All right. I guess that makes sense. And medically, did you find that the doctors were like us as the only option. Even you voiced your concerns.

A: Yeah. I think he does. I mean, listen my husband's got ADHD as well. So like, there's a little bit of zoning in there. [R: Apple. Tree.] Yeah, totally. There's Yeah. So yeah.

R: All right. Well, thank you so much for letting me ask you more personal questions. [A: Pleasure man! No problem] And I will not take up any much more of your time. I just wanted to say thank you so much for such an interesting discussion. [A: So welcome. I hope some of it was helpful.] No all of it incredibly helpful. And so basically now I'm going to transcribe this interview and then I will use it in analysis with S and G's and just trying to link it with what community means to everybody. [A: Nice! Well done. Good luck.]

Transcript of interview with Raeesah (Yusuf)

Codes	R= Researcher	M = Mother	
	(text)= description	[text] = adds a word in	*Text*= emphasis

Background

I first met Yusuf in 2021. He was largely non speaking and had a few gestures and vocalisations that he used consistently. Raeesah was in attendance for all the meetings and all the events at school and showed up for Yusuf always. Yusuf has made beautiful progress with regards to his communication, visuals being the key to his understanding and expression. Still, Raeesah has shouldered a lot of deciphering and explaining to others who do not know what this means.

The family was contacted verbally to participate in the study. Once initial consent was obtained, the interview was then scheduled via WhatsApp. The interview took place in person at Yusuf's School. The interview was conducted with just Raeesah but Yusuf, his sister and his father were around, playing on the playground. Raeesah were given a bit more background to the study and the researcher clearly explained the difference in relationship for the purpose of the interview (i.e. Therapist vs Researcher). The interview took place as follows:

R: Beautiful. So thank you so much for being here today [M: it's a pleasure]. And so one of the starting points of why I chose this topic was we had a little girl that used to come to Kanyisa. And she had autism, she was also nonverbal. And she, her family had a really difficult time with her. She had big emotions, so lots of meltdowns when she couldn't get what she wanted, and that kind of stuff. And eventually, they emigrated to the UK. And we still kept in touch with the family. And they kind of just, they were telling us the kind of services that are available to them in terms of her having a disability. And, like, you know, the airport staff had training on what on how to handle her. And when they go to their shops, they have something called sensory our which is where they dim the lights, and they shut off the music. And it's just an easier place for her to be. And she was like, I've never experienced anything like this before. And it just got me thinking I'm like, oh, that makes so much sense. Because then the burden isn't [M: on the parent]

M: I see the child at home. 24 hours, right? We need to get them out. [R: Exactly]. I believe that overseas has integrated these children into their lives. Sorry for the word. [R: No, no]. I know a lot of people get offended by it.

R: But yeah, you use whatever language was comfortable for you. It's just your story. And you own it.

M: Yeah, so with Yusuf, he was born in December 2015. My whole pregnancy, we didn't know that he had Down syndrome. From the time that he that I gave birth to him. The doctors didn't know how to tell me in an appropriate way. [R: How do you mean?]
So the doctor told me the day I gave birth, he said everything is fine. But Yusuf had to be in the ICU because he was little. [R: Okay, yeah. Was he born preterm?] Yeah [R: okay]. So the next day, he tells me, you know, the nurse has picked up a few signs as Down syndrome. But we go into do a blood test to find out, but there was no sitting me down. Do you know what Down syndrome is? You know, no,

explain it. Oh, just just like that. First, who told me that is fine. Then the next day in passing not came to sit down or chat to anything. That's how he told me. And then they did the blood test. And it took I think two weeks, we were still in hospital and another doctor in the exact same way. My husband was in present, I was the only parent there. First time mom, Yusuf has no siblings. And that's exactly the way he told me. No explanation, or no, your life is going to be fine. The only time we realized her life is going to be fine. Is when he was I think one and half [R: Okay]. When like he started doing the normal milestones. Sorry, this story is very long [R: of course]. Anyway, that's so from the doctor's nobody gave you a positive that you know that you're going to be fine. He's going to be different. He's going to be slow, but you're going to get through it. And he's a person he's a child, that that his story can gonna be the burden, then your life is not going to be like everyone else but anyway it was. It's just slow. So anyway, then we started all the therapies from I think about one, but Yusuf was slow in everything. Everything. And he's very much he won't go without me holding his hand. He has to have somebody, or he won't just run. But now since he joined Kanyisa wonderfully he's running with all the other kids (R: laughs). He still won't go and do things on his own the climber obstacle course he won't, but the fact that he's running after kids is something that he did do so Kanyisa has really highlighting a school background and [R: just that socialization for him] has been [R: amazing]. So that's, so that's where we are. But Yusuf can do a lot of things. But I think his hands his hands fail him a lot. He can't do things with his hands. And in the speech, he can't talk, but he can gesture. He can take you to where he wants to. He knows how to get his way with with (R: laughs) just gesturing and [R: yeah, lots of sounds] and he knows what he wants. Yeah, and you understand 100% Except the word no (R: laughs). That couldn't understand.

R: Yes. He's a feisty one when you use no (laughs) [M: yeah]

M: But it's not that he's trying to be aggressive [R: No]. You don't know how else to tell you because you're not listening. [R: Yes.] You know this from you that listening, [R: that that's communication].

M: I don't want to eat that apple forced me down my throat, I'm going to hit you.

R: Absolutely. And we love that. Because I mean, that is kind of like [M: communication in its own way]. Exactly. Every behavior is a communication, your child is laughing, crying, hitting everything is communication and all mean something. And again, that's like, kind of as a parent or someone like Yusuf, you are, you are the dictionary, you know, hitting what that means when he takes you what that means when he makes a noise. You know what that means?

M: That's where your research comes in handy is where the community needs to learn what that means. Hopefully it will do good.

R: Yeah. I know that the story is emotional for you. But could I ask a few more questions? [M: Yeah, yeah]. So when so when the doctors gave you that information, they obviously didn't give you a lot of background? How did you kind of say, okay, this is what they've told me about Yusuf [M: what does it] what does it mean?
M: Luckily for me, before I got married, I was working for a remedial school. [R: Okay]. Yes. So your child is not equal to the next child. So it was still completely different. But I had some insight about what exactly a Down Syndrome child is, the children there were doing exactly the same thing as a normal child, but a bit slower. So I knew I knew what Down Syndrome meant [R: okay]. But for you, as a person, you don't think you're ever gonna have a child who has Down syndrome. So that was so

hard [R: Yeah]. Although I knew that child will be fine. Yeah. Yusuf had no medical issues. [R: Okay]. That was a big thumbs up. [R: Yeah]. So, you know,

R: I was just asking about how you found out?

M: So Google helped me a lot. [R: Okay]. Yeah, Google really helps. Exactly what is down to syndrome, what's going to happen in the future, reading, reading is the only way that I could find out. And then when we did go to therapists, and they told you a bit more about what's going to happen, and his strengths and his weaknesses. So it was all the learning curve. And I took it step by step. And I didn't rush and go and go to the library and take out books. So it wasn't a great deal of going back and forth. But Google and books out.

R: Okay. And in terms of like finding out what therapies you would need also from Google?

M: The pedi… pediatrician, [R: okay]. And, of course, other moms with Down syndrome, kids. So you need to start researching on your own. So the, actually the moms groups helped a lot having mom's groups really, really helped.

R: But you had to find them yourself?

M: Yeah. There is a Down Syndrome organization.

R: Not a lot of information or support?

M: The only support that you'd really get was the moms groups, the Down Syndrome groups, and I did join a Facebook group with international Down Syndrome, that *really* helps. [R: Okay], they all went through the same things that you go in, and if you need tips and hacks and all of that, that's your go to. So I think the biggest support group is your mom's groups.

R: Okay. So social media has been helpful in like, kind of bringing that virtual community to you. [M: Yes]. Okay.

M: Yes. And there are quite a lot of moms in South Africa, in Durban.

R: okay, all right. And then just in terms of the way things were handled, when Yusuf was born, what do you think needs to change for it to be better for parents?

M: Doctors need more need to learn emotion. How to handle these situations and how to talk to people. That's what doctors need because it starts from there [R: Yeah]. The community needs to know how to speak. How to talk. No, just be kind [R: Yeah], things are going to be okay. It is normal. [R: Yeah]. You don't want to hear it's not normal. You only hear it is normal but its slow [R: yeah, like you will get there]. When he is ready.

R: That's the wonderful thing about Yusuf is that he lets you know when he's ready.

M: Yeah, with everything.

R: Yeah. And that's a wonderful thing.

M: When you speak to him, you can't rush him, like if I asked him to go throw this in the bin, but ask maybe two or three times, and yeah, the biggest problem I do have with Yusuf is he's watching way too much TV [R: okay]. And its very hard to get him off. [R: Okay]. But it's making him happy. [R: Yeah]. I know people. A lot of people tell me, he's watching too much TV, but it's making happy. [R: Yeah] He's learning from it, somehow. He dances to the music. He laughs when they doing something silly. [R: Yeah]. It's sort of a social thing with him also, because he was the only child. It's helping him to, to laugh and be happy [R: yeah], so I don't see all the bad in it. Yes. It might be bad but it is not all that bad.

R: Yeah. And I'm sure for you as a parent. You also need like, [M: timeout]. Timeout for yourself.

M: Cook or have a cup of tea or something.

R: Exactly. Yeah. And how has he adjusted to be an older brother?

M: When she cries and stuff? He doesn't like it. That's her communication. But he doesn't see it like that? But if he cries then its fine [R: Yes]. You know, because then he attacks her. [R: Okay that's hard]. It is hard. He gets a lot of scolding for it. But he doesn't see it as I'm doing something bad he is trying to make her keep quiet.

R: Yeah. Again, that's his way of saying like, [M: why] Yeah, exactly.

M: That's his communication. Like I said, he's hitting, but it's to tell you something.

R: Yeah, okay. Alright. Okay, so that's when Yusuf was born?

M: Yeah. So basically, the doctors need to know how to talk to parents. Don't rush through it, because you got 10 babies to see to don't rush and give them your five minutes. I'm paying you your bill. I need at least half an hour of you. And he said that the nurse picked it up. It wasn't even him that picked it up.

R: Gosh. Okay. I suppose that also leads back to the time, the amount of time he spends with you said the nurses are spending more time.

M: Five minutes he gives my child and it's a R1000 a day.

R: It's so crazy when you think about the power dynamic of being in a place like a hospital. And like the doctors are rushing in and out so much that you forget almost that their job is to serve you to help you. And you're kind of like this weird power dynamic where they're like almost in charge and you don't feel like you get to ask the questions or have the time with them. But it's actually them that need to be with you.

M: You are the one with the medical knowledge to pass on [R: Yeah], you're not doing that because you got 10 grand to make.

R: It's wild and Raeesah. May I ask, what was what was what was your family response?

M: Very good. Community wise have been very good. [R: Okay] nobody has told him as ill anything ill. They do like to tell you what to do.

R: Okay.

M: Yeah.

R: Did you get a lot of unwarranted advice?

M: Yes. Like especially now it's more irritating because they tried to tell you how to handle him but he's different. I've seen a lot of Down Syndrome children and from all the Down Syndrome children, they all different and he's got his own difficulties his own. He's easy in something using, difficulty in other things and everybody's different. So you can't tell me how to bring him up me knowing best [R: absolutely]. Yeah, so everybody's different Yeah.
R: What kind of things do they say?

M: Like currently, currently they telling me to put him in a normal school [R: okay] because then he'll pick up vocabulary [R: Okay]. Like he is not going to adapt to a normal school, you know, you see him. [R: Yeah, absolutely], definitely not going to.

R: I mean it will be a huge jump and I like I understand where their intention is coming from. It's wonderful to have a verbal model and you know, have kids talking around but he does get exposed to that here and has learning just takes a little bit more input and effort.

M: hello Yusfie! [R: you made a friend?] can you say hi? Can you give her a high five?

R: it's very confusing.

M: You can go outside. I've got this. Bye

R: (laughs) couldn't imagine it's so confusing for him to be here on a Saturday, and his the only one here. Do you want to go outside too? She’s got such a big smile on her face.

M: She’s calling Yusuf. Oh, she loves you. But she's afraid now. [R: How old Is she?] 14 months. So what were we speaking about?

R: Oh, just the kind of advice you were getting.

M: Oh, yeah. So I must put him in a normal school because it will benefit him. Why don't I leave him to run with the other children? If I leave him to run with other children, he will sit and he'll watch them and he won’t make an attempt to go, like I said, I have got to go and push and encourage him. So I don’t have time to sit with the moms and talk. It is what it is. I've got to take him. So if you look at my at my social battery 10% is just eating with the moms and 90% is taking him out which I enjoy.

R: Yeah, it's a lot of fun on the playground. Yeah. Okay.

M: But he needs a lot of encouragement.

R: Yeah, he is quite reserved, especially when it comes to new people, and new kids

M: washes, everything.

R: And he's a *great* observer. He is like, he's got such a keen eye for whatever is happening around him. And that's also the way he learns.

M: he doesn't even have to look (R: laughs)

R: Absolutely. Okay uhh Raeesah I wanted to ask you a little bit more around inclusivity and belonging, and what that would mean for you as a family and what you would want to see for Yusuf.

M: So, like, with the children, I feel that the very fast and they just run along and then he is standing and looking. So if children at school would be taught about different child. It's fine, that his different. But we've got to also take him along, and play with him and show him around and just be a bit more aware that he is there.

R: I don't know these kids that you, that you when you're in public like at a park or at Ushaka or on the beach or wherever. So it's not like children that are within your direct community. Like your family, his cousin's, his neighbors, it's [M: it's a whole community. Everybody.]

M: But he loves to go to people and talk to them and stuff [R: yeah]. Loves high fiving (R: laughs). But he he won't just run along and play with the kids. Kids can just be taught more about it in school. Then he would also be included and stuff. Well now I see that a lot of the kids take him along. [R: Oh good! So kids are familiar with him?]. While he's chill, he's his family. But, but everybody in the community loves him and talks to him. And to that makes him feel included. Nobody leaves him out as such, but I feel like in schools they need to be taught more [R: okay, that's fair].
Yeah, that's otherwise I have no issues with community. They all brilliant, everybody talks to him and everybody loves him. He's like, like you said before he's a celebrity. [R: Yes], he is. I think also, because he has cute features, everybody wants to know him.

R: Where are those places he is a celebrity?

M: Everywhere in the malls, public places, like restaurants. [R: Yeah], everywhere, but everybody wants to know him. And now he goes in with all the men. He goes and shakes the hands when he's leaving
[R: That's beautiful]. When he goes in and shakes everybody's hand. He likes people and people do love him. [R: Yeah. Yeah]. Like I have no they all include him. [R: Okay]. It's just at schools they need to be taught that even if something looks different to you.

R: Doesn't take much. Okay. And and for when Yusuf is older, what does that look like for you? Just for him what you want him to get out of life?

M: I just need him to be happy, happy in his surroundings and happy with his life. But my number one goal at the moment is to get him independent. [R: Okay]. Yes. A lot. I do a lot of things for him. But like you said, his hands do fail him. So independence is hard. [R: Yeah. Okay]. Basically, his therapies need to help him.

R: And do you feel …

M: And also sorry [R: yes] that you have to have money in order to get him to where you need him to be. There's nothing that 1800 Rand that they give you, the government gives you isn't going to help. So we need more free service.

R: Hmm that's an excellent one.

M: Free service to help them every day they need therapy its not just once a week isn't going to help. Or even even if you do need to do it once a week then the parents need to be shown how to help. [R: Yeah], but you have to have money [R: in South Africa, yeah you have to have the money]. Therepies are expensive. You have to pay like two grand. [R: Easy].

R: And then sometimes its not only the therapies sometimes it the therapy and if it goes to OT he needs a special grass or whatever then it's additional on top of [yes, everything is money. So that 18 hundred doesn't help]. But you do need other organizations to maybe open up a therapy room with the less fortunate can bring their children.

R: Yeah, absolutely.

M: Even for us we weren't always able to pay. [R: Yeah], which things make things? [R: Yeah]. So like, you know now but you don't know next year if you're gonna be able to, you know.

R: Covid hasn't helped at all. [M: everything stopped]. Yeah.

M: Especially for Yusuf it was very hard cause then everything stopped.

R: Cause he came before for enrollment screening before hey and then everything happened. And then you had to come back when it was safer [M: yes] a little bit safer.

M: Everything stopped.

R: Unlimited access to things that you know would have been helping him. Did you try teletherapy.

M: What's teletherapy?

R: Teletherapy a lot of therapists were taking on during Covid and it was basically like via Zoom, online, through a screen.

M: We didn't do that.

R: Its hard, I mean we tried it with our kids and it was really hard like we lasted maybe like two weeks.

M: Only the parents would be able to sit and watch a Zoom meeting.

R: Mmm, absolutely. I love that free service idea.

M: Yeah so free services, or not even free, you can charge something, it doesn't have to be all free but something where the less fortunate can come [R: yes]. So that and more talk about it in schools, uhm, so this is for Doctors to be able to handle this kind of thing.

R: And just had a thought while you were just summarizing there, uhm, in terms of going to the schools and like the kind of talks the kids get. Do you think that it should be therapists? Do you think they should be parents? Do you think, who should do it?

M: Parents but also like if you can bring group of Down Syndrome or Autistic, children with special needs to the meeting or to the assembly point or whatever you have and maybe let them meet the children.

R: hmm, that actually such a wonderful idea because we have so many schools around us as well. We've got Chelsea over there, we've got Fathima over there. Like what would it take to just get them here for a break time for one hour.

M: I think the younger kids more.

R: Yeah, Chelsea prep I think

M: yeah, yeah, Chelsea, Gordan girls is not far.

R: not far there is a lot of schools in this area.

M: even like, people that, children that are like going to study in this kind of field, they can come have a look at the kids, be around the kids. It will help somehow.
R: Yeah, that's a wonderful idea. Okay.

M: So even, so like, like you were saying about the autistic children, if you can get the businesses, businesses to uhm, shut down their lights for an hour to allow for, especially adult autistic children, when they start to come in. So you can alert or give them some information about that. The business sector.

R: That's been my dream, since like my first year at Khanyisa. And it was just so hard to like get a foot in the door. So we had emailed between Amy and I. We had emailed Spar, we had emailed Checkers, everything like in our vicinity. It was just really hard, the only kind of place that came on board was, uhh, I don't know if you know the Pick 'n Pay on Chartwell Drive in Umhlanga. In that little Chartwell lighthouse center [M: oh yes]. They actually uhm helped us for like half an hour one day, one of our older classes, we went and we were doing kind of like a prevocational lesson. We are going to make this, we need to go get the ingredients for this so lets take our shopping list. We are gonna go to Pick 'n Pay and the manager was amazing so he didn't like close down the store or anything but they had a few like assistants from around the shop taking the students in like small groups [M: yeah] and go do the shopping list together [M: that's nice].
They helped them from like the door to get like baskets and they went and they got everything and they like cleared a few tills for them so they can just like pay and work with money and that. So that was really wonderful.

M: Is it really a problem when the Autistic children go, go out?

R: uhm it depends on the individual child, I guess. So we had also done so much preparation before we went. We did the social story. We're going to the Pick 'n Pay, they let us come in and take photographs of the shop before so they kind of knew what to expect. Uhm I guess its different for each child, different for each family. Uhm the little girl that I mentioned whose family is now in the UK, they kind of like, it just became so traumatic for them that they just kind of stopped taking her places because you never know and she was, she was very attracted to like little baubles, shiny things. So you never knew what was going to come up in an aisle and she would be like oh I really want that but its not something you can get her kind of thing.

M: I think it was really help if you get the business on board to do this because now there a lot more children with Autism, Down Syndrome and so forth. Maybe not all, maybe a few, community, like you said Umhlanga one. Maybe Windermere. Not the big centres, just the small ones [R: Yeah].

R: They do, they should have a presence in the community like it shouldn't be new for people to see a child whose different.

M: Its not new, theres so many. Theres a lot. And I think uhh people want business so if they know that this will help the community. Good to approach.

R: Yeah, that's a brilliant idea!

M: But you need all of the schools, maybe all the special needs schools should write a petition. I am sure there are quite a few special needs schools that will think that will be a great idea.

R: Yeah, definitely.

M: Maybe the community of therapists as well to write to. To the commerce [R: hmm, make a big deal, make a lot of noise]. Yeah.

R: Yeah absolutely.

M: Cause now everybody is online so that will make things so much easier. To just do it online but you need to take your kid out [R: yeah]. With Yusuf I'm blessed that he has no problems going out. He loves to go out. So we have no meltdowns (R: laughs) or anything. So I'm so fortunate [R: Good], uhm yeah, [R: okay good].

R: Uhm yeah then we chatted a bit about belonging and what inclusivity looks like for you. Have there been any experiences uhm with Yusuf where you have felt excluded or where you felt like you haven't belonged or? [M: No], or that somebody has looked at you funny.

M: No, nothing [R: Okay], nothing. The community has been amazing. They love Yusuf. The only thing that I do feel sorry for Yusuf about is that the kids are too fast for him.

R: Okay, yeah.

M: But maybe its only Yusuf, I don't know because Yusuf is a bit different to the other kids. Even to the other Down Syndrome kids. I know lots of people tell me that their Down Syndrome child can

remember so fast and runs about. Like Yusuf is different. His personality is different [R: yes]. So maybe it could only be Yusuf.

R: Its so funny how like our expectation of typical kids or even typical adults. You don't expect me to be the same as you but when we say a child has Down Syndrome, we almost group them into [M: all of them are like that] all of them are the same [M: yeah]. But that's not for us, its for them.

M: we all have personalities. His very cautious [R: mhm], very timid. That's just him.

R: he can be quite sassy though when he is familiar with you [M: hmm]. His got a big personality when he knows you.

M: I think of am I comfortable with this person?

R: Cause if I can, if I can just like reflect on what Yusuf was like when he first came to Kanyisa. It's exactly what you said. He was timid, he was quite shy. Little hesitant to meet new people. But now when he knows your face and he know his peers, he knows his teachers. Its actually amazing to watch him in his environment and what he can do. He is very capable of saying I like that, I don't wanna do that, get that away from me.

R: okay beautiful.

M: I hope I'm helping.

R: no, you are. This is beautiful. So its very apt. its actually very little about speech therapy but more about the world and the community.

M: You said you wanted to know about the community.

R: yes, that's exactly it, that's exactly it. So, its not about, its not about how my direct speech therapy can impact but I have this knowledge around communication. So like Yusuf who doesn't use a lot of words, but he uses other ways of talking.
I have that knowledge to know what can be done to make sure that his communicating and I feel like I have a responsibility to share it with people that's not just you so I can teach you Macaton for example, and then you know Macaton and the Yusuf goes to Pick 'n Pay and he asks for a drink and then they're like oh I don't know what this means (laughs). So that's where I'm getting at I'm getting very frustrated where I'm like the burden shouldn't only be on the parent [M: or on the school] yeah. Because Yusuf needs to be independent and its, its actually not his fault that he can't be independent. It needs to be more on us that we can do more for him.

M: So basically as im sitting here right now, I know that in the future I need help, a helper for Yusuf. So if im not here one day. I need somebody to be able to take Yusuf to the store and get him what he needs. So I know that as the world is right now he cant live on his own. So we need somebody to guard him.

R: Yeah, and the get the frustrating part is I know South Africa is quite different. We have our own set of challenges but like there are places like in Australia where uhm you know they have like adapted homes where you like there is a floor of like five children and there is a person that manages that floor

but they get to live independently in their own little like apartment and make their meals together. That person is there to help them with finances and they go places together. The help them with jobs. There is a carpool and that person takes all five of them and drops them off at their job, fetches them in the afternoons.

M: They don't have that and we don't have jobs for them. We need jobs for the.

R: and good jobs for them. I feel like sometimes the recommendation is you know, they can pack the bags at supermarket and 100%, that's a very valid job but are kids have so many different talents and so many different areas that I feel like we need to think a little bit more out of the box.

M: its not just pack the shelves; they can make it beyond the till [R: hmm].

R: and maybe we haven't even invented jobs that they can do yet but I feel like just need to, we need to broaden our vision of what the world looks like. Because we're looking at through that very neurotypical lens of what we can do.

M: I know that Cape Town has a restaurant [R: yes] do you know about it?

R: brownies and downies I think its called.

M: It's a lot of special needs kids and uhm we need more like that. That will be fun. In terms of speech therapy for non-verbal kids, its not going to happen. We cant get the ACC, how are you going to fit that in to a shop.

R: But there are already using, using alternative communication everywhere we go. Some even like McDonalds. In some McDonalds you can go up to the teller, and McDonalds have those boards [M: to pick what you want]. Exactly. So we are actually already using alternative communication in shops so like things like that are, hey, we can definitely jump on that.

M: even like you say uhm maybe the people go with their Ipads [R: hmm] yes, that's an amazing idea. Where the companies need to know that look uhm a non-verbal child can come in here and show you exactly what they want on their ipad. That's actually a good idea.

R: 100%, that's a brilliant idea! [M: yeah, everywhere]. Yeah everywhere! And if you think about it in the way that like we communicate I mean even we message over Whatsapp. I can use emoji's to show you how im feeling. Like that's all alternative, its not necessarily just speech. So I think we're doing so much more than we realize of communicating alternatively. Its just when it comes to these kids, and our kids, like where is the barrier coming from? Because we're doing it and its okay for us but its not okay for them [M: true].

R: Raeesah, I have a few more questions for you. Uhm, so, we chatted about what environments can look like. For you the biggest thing was that the kids need that input into knowing how to interact with Yusuf and it would make all the difference in the world for him. For you. Uhm I just wanna hop on over to ask you for your family, what is your support system? What does that look like for you?

M: Grandparents. Family. Uhm family is the biggest support [R: okay]. But with Yusuf I do everything for him [R: okay]. Like when he was born and like, I got the news. My family they the ones that told

me its fine [R: okay]. Didn't make me feel like what did you do? What did you eat? My family around me they really supported me [R: okay].

R: and what do you need that support to look like? Just like they're available when you're having a bad day and just someone to pick up the phone to call or someone to take Yusuf for a few hours. Its been a heavy day. What does support look like for you?

M: uh, okay, so people take him if I need to be out and whatever [R: hmm], they are always ready to take him to be with him. But he cant communicate with them [R: okay]. So I have to be with Yusuf all the time [R: okay]. Like taking him to the toilet, his a big boy, taking him to the toilet and that's difficult for other people [R: okay]. Even feeding time, all of that [R: okay].

R: So you can leave him with other people, for like those short stretches of time, if its maybe like half an hour?

M: yeah even an hour but I don't let anybody do things for him [R: okay]. Cause I feel I know best (R: laughs)

R: okay, that's fair, im 100% certain that you do know best (laughs). Would it ease your load if people did know what to do with him? How to take him to the toilet. What it means when his looking?
M: So that's where the communication board would really help other people.

R: Okay, he is really good with his visuals, Yusuf [M: yeah].

M: So I feel like that needs to be at his grandparents house [R: okay]. That needs to be with those that are close to him [R: okay].

M: But Yusuf is not a difficult child [R: no his not].

R: So how do his grandparents communicate with him now?

M: He gestures to them [R: okay] he knows how to communicate with you [R: okay].

R: So just almost a bit more clarity? So he needs gesturing?

M: so if he knows his communication board well and he knows exactly what to tell on the communication board. Then he can communicate wherever he is [R: okay]. So communication board is really something is just mind blowing and everybody needs to have it within the special needs community. Cause if you, if you can unlock that with your child, then there is no need for him to say a word. Cause its got everything. Its got that im angry, im sad, I need to go here, I need this. Although, it easy to pick the wrong thing [R: hmm]. So really needs to know what they need. How to use it to communicate [R: yeah, absolutely]. Because there can be a yogurt and a chocolate and his gonna pick chocolate [R: yes (laughs)].

R: yes, and then can I ask, you're so open to the other forms of communication. What was your thought process into that? Because I know its quite a difficult concept to let go off my child is not talking now. What does communication look like?

M: Kanyisa, I didn't know about the communication board. When he was younger, the therapist told me about the communication board but it didn't make sense to me at the time [R: okay]. It looked like pictures but Yusuf does not understand what this picture means. Like okay for the stop sign, Yusuf isn't gonna understand. Actually she just gave, she just emailed that to me and told me to teach that to him. So that didn't make sense [R: yeah]. Until he came here and now you showing him, now he can understand what you're telling him so he can pick the right one. He doesn't want to do this activity. Showing you this sign. So it takes a, it depends where your child is understanding wise to be able to use the communication board. You can't just give it to them at any age [R: absolutely not] yeah.

R: if I, similar to if I had like Raeesah we're gonna learn French today and I just gave you like a list of French words and phrases. Its not gonna teach you the pronunciation, its not gonna teach you what any of that means. You also need to look at that alternative communication as a different language, we need to teach it the way he needs to learn it [M: yes]. Because we're giving that like verbal feedback or the time and he doesn't have the access to those visuals and we're not teaching him that way. We're basically asking him to learn a new language without giving him the support.

M: yeah, I don't know, some of the therapists and Doctors have really blown me away.

R: In a good way or bad way?

M: No in a bad way

R: okay (laughs), im so sorry.

M: Oh my god, thinking about it now, she just emailed it to me. It didn't make sense [R: hmm]. How is Yusuf gonna understand what it's a stop sign?

R: Hmm, and how often was he going for therapy?

M: Once a week.

R: For SLT? [M: For everything]. OT? Physio? Okay, gosh im so sorry that you had that experience [M: yeah].

M: Some people have done really well theoretically but when it comes to putting it into action they don't know how. Unfortunately. So again, they need to be taught empathy and all of those things.

R: Yeah, absolutely. Uhm let me just check. I think that I have asked you all the questions that I needed to ask you.

M: is there anything that you? That I didn't? That wasn't clear or [R: uhm], do you need from different perspective? [R: no] cause I gave you answers on community. On what the community needs. I didn't give you answers on speech therapy.

R: No, you did absolutely perfect. That's exactly what I was looking for. Its that more community impact rather than SLT. Cause I think its easy for us for us to fit in to community, whereas community

doesn’t always fit in with us. In how we practice traditionally. So its more for me to get an understanding of what your community looks like and then I can like. I can have an idea and be like oh okay, this is what you’re saying about the community. The kids actually we need to start young, explaining to them what children are like with disability or they are different.
What we can do to make sure they feel included and loved and happy and yeah just feeling good in a space. So that’s exactly kind of where was I was hoping because I think its something so like easy for us to do if we just branch out a little bit more. It's really easy for me to walk up the road and say, hey can we have 10 minutes of your time?

M: Also with his granny, she really wants him to talk. Six years, he hasn't said anything. Like, I need people to understand that there are other ways that he can communicate. Other than words, I don't know why we can't talk. Because he can chew properly. He knows what he wants. It's just the brain isn't synchronized with his mouth. Probably. But that's that is where we're at. If you can use pictures rather than words fine by me.

R: And is that pressure on you? When Yusuf can’t talk.

M: Yeah, I and feel bad or anything that he can't talk when other people make you feel like you're not doing enough? When you let him sit on TV the whole day, and that's why he's not doing what he needs to do, but that's his personality. That's who he is and what he enjoys doing.

R: Sorry, no, sound detected. We're fine. Okay. That's a lot of guilt on your part to feel with when people. Yeah, I've seen that kind of thing.

M: I'm know that they mean well and they don't understand fully. Like there are a lot of other Down Syndrome kids that can talk. Why can't Yusuf talk? Because you’re not doing enough. And God knows why his students do such and such things.

R: But again, it's that whole label. Children with Down syndrome need to say things with the expectation there's stuff that you and I was saying,

M: Like I did see another adult who couldn't talk. But then there are other adults who are doing brilliantly and can read, you know, our Quran [R: hmm] they can read the Quran and they memorize Quran [R: Okay].

R: Now that you mentioned it, your religion being Muslim, what do you find that, there are things do you find that it has guided you, in how you see Yusuf? [M: from Islam?] Yeah, from a spiritual perspective, religious perspective.

M: We say that he is that Key to Paradise. Our key to paradise. Because God gave you a special needs child, which is not normal, and he expected you to live with it. So if you look after him properly and have patience with him and stuff, and you will do good in this world, and then you're gonna go to to Heaven. Hopefully.

R: 100 percent. That's beautiful.

M: Yeah. And we that's the way we see it. God gifted it to you. It wasn't a genetic mistake as people say, he knew what he wanted to give you. And he gave you an opportunity to enter heaven through your child.

R: I love that.

M: To stop whacking him on his butt when he doesn't do what you want to do and listen to him. Because he knows what he wants to do and what he's capable of. But you pushing him to do something that you think is correct.

R: Okay. And do you think that having you served with him having Down Syndrome has impacted your family dynamic?

M: Just made us stronger?

R: more resilient?

M: But it would have been nice to have him as normal. God gave you what he wanted to give you. Well it was hard having your first child with Down Syndrome. Would he have been? Or maybe not, it would have been easier if he was a second child. Because its something that you think is gonna be normal. And you had dreams about him and his dad going to the beach and kicking the ball and playing rugby. But it's not the case. [R: Yeah]. So that was hard. But he's a beautiful child. [R: Yeah, he is]. Well, now that we got her. She's a spunk.

R: I can imagine.

M: Yeah. Absolutely.

R: And have we given any thought to how you're going to explain to her?

M: I do know that there's a lot of books.

R: There are a fair amount of books.

M: Yeah. But she can see that his different.

R: In what way?

M: his behavior.

R: Okay. So what you were saying before, like, if she's crying and she gets upset.

M: yeah, like, even with what he can do and what he can't do, she can see that he is he can't kick the ball, or he e can't push, like if she wants to play, he can push the ball directly to her. She can see that. He doesn't play with her like how she wants to play. [R: Okay], so in that way, she's he's not doing what she's doing. Like, he'll take the ball and spin it while she wants to push it.

Okay. All right. She'll learn over time, I'm sure he will too. Learn from each other.

M: Yeah, no, no, no, no. The biggest blessing is that Yusuf was never a copycat. Until she came (R: laughs) she race him to get to the lift, she wants to press the button. So now I tell I say, okay, its Yusuf's turn and comes to press the button [R: aww], with so many things. It has been in the same manner. She whatever she does, he does. [R: Yeah], so there's a big competition. Should I think that's a better word. [R: Okay].
It's competition, when it has helped him because he never ever wanted to push the button on the lift. But now it's her first. It's Yusra first and then Yusuf, okay, so copying. He does that. Before we used to do it, but never worried about copying us. So maybe sounds will come in time with …

R: once he has the challenge.

M: Yes.

R: Yes, exactly. Uhm beautiful Raeesah. That is that is all I have for you. That's all my questions. Thank you so much for your honesty and for your vulnerability. I just really appreciate it. I know that these were not the easiest questions in the world to have asked.

M: No, it's a pleasure hoping that it will benefit you in your studies and community as well so that when Yusuf is older, it'll be easy, but it is really taking him out and stuff is not hard. [R: Okay]. It's not hard for me personally, but maybe for the other children it is. But life with him, inclusivity and everything, kids, people want him and do a lot for him instead. It's just for Yusuf personally he needs to be independent. [R: Yeah]. But he's got a lot of problems with hands and one of those things, a lot of sensory issues.

R: Yes. I think that's also why you see that behavior. Sometimes she's crying because it's loud and all of those things. Okay, that makes a lot of sense. Thank you. That was a beautiful summary as well. I got everything you said. Thank you so much.

M: I really hope …

Transcription of Caregiver Interview - Aliza

Codes	R= Researcher	M = Mother	
	(text)= description	[text] = adds a word in	*Text*= emphasis

Background:

I first met Ncebs and Aliza in January of 2022. She had just enrolled Aliza into the Developmental Centre where I worked at the time. Ncebs was quiet and unassuming, but a keen observer and a fierce advocate for Aliza. She was a fountain of knowledge and as a mum who as always had to, was quick to explain. When Aliza was sniffing you, Ncebsi explained it was just her trying to understand who you were, when Aliza was tapping her chin, Ncebsi explained it was just her stimming.

When we started working on Toileting with Aliza and the Occupational Therapist, Ncebsi went to a hardware shop and asked for leftover tiling. Because the bathroom at school was tiled and Aliza was learning that the change in texture on her feet meant it was time to sit on the toilet. And there in the open, informal dwelling where they lived, was a corner of tiling so that Aliza knew where she was going. It was a simple, matter of fact piece of information that Ncebsi shared on a Tuesday morning but it spoke absolute volumes about who she was as a mother and caregiver. These little acts were incredibly powerful. She was incredibly powerful and I had no idea until the interview started, just how powerful she was.

Ncebsi was contacted verbally to participate in the study. Once initial consent was obtained, the interview was then scheduled. The interview took place in person in a sensory room at the Developmental Centre so that Aliza was in a space that was comfortable and known to her while the two of us talked. Aliza was in a ball pit, content and settled. Ncebsi was given some background to the study and the researcher explained the difference in relationship for the purpose of the interview (i.e. Therapist vs Researcher). The interview took place as follows:

R: Okay, Ncebs, thank you so much for sitting with me [N: Thank you for having me.] (R: laughs) today. So I just wanted to explain to you a little bit about my project. So I'm doing my PhD in speech therapy. And so what I found that is when working with our kids, like, I can see them in the classroom, and I can do therapy with them. But then often, it's the parents that need to take on everything that I say, or the teachers, but then what happens outside of Khanyisa? So a lot of our families are under a lot stress, because it's their responsibility to carry over everything. But what about everybody else? Like, what about our community? Where do they stand? They also need to be understanding, like what's happening. So for an example, like M(child's name) in the Yellow Class, he uses his iPad to communicate. But we use it, and his mom uses it. But what happens when he's older, and he needs to go to Pick n Pay and ask for help? Or like ask for something? People there don't know how to use it. So that's where I'm thinking like, how can we get more people involved in understanding how our kids are different and how we can help them. So obviously, Aliza comes to Khanyisa. So, I just wanted to ask you a few questions about her, about you, about community. And what that looks like for you?

M: Yeah

R: Amazing. Uhm so first things first, let's do a little bit of background. Can you tell me about your family? [M: Uh] Oh, introduce yourself as well.

M: Okay (laughs) My name is Ncebsi Dotwana. I am 24 years old (deep breath in) and Aliza is my daughter. She's four. We currently stay here in Durban [R: Mhm]. But we are, were born in Eastern Cape [R: Mhm] in a small town called Bizana [R: Mmhmm]. That's where I grew up. That's where I spent a lot of time [R: Mhm] and ummm…my…my parents they are no more [R: Okay, sorry]. Yes, I think I was seven when I lost my mom. [R: Okay] then I don't know about my dad [R: Okay] Yeah and now I am currently left with my…my mother sisters. Those are my family. Uhmm, and they also have got kids.

R: Okay. Are they in Durban?

M: No, they are in the Eastern Cape. I'm the only one who's here. And Aliza. I don't have any family around.

R: Okay. And why did you move to Durban?

M: Um, it's because of…I felt like Aliza was not getting enough help back in the Eastern Cape. To the hospitals that we were attending, like, the services were very poor in such a way that I managed to research other hospitals [R: Mhm] here in Durban. Then, I came but like, I came, I tried to look online and I came to the hospital. Then when I got here, I met some people [R: Mmm]. Like they helped me with accommodation [R: Okay] until I got my own place to rent.

R: Okay.

M: Yes, that's how I came here in Durban. Because of Aliza's situation.

R: Okay. Tell me about her.

M: Hmmm she's a lovely person. Like like she's active [R: Mhm] sometimes she can get angry easier and she's a strong child. I can say. She is very strong because like, the way she is taking everything that is happening to her like she like, now she is deaf blind [R: Mmmhhmm]. So like, the way she is taking all of that, like, she to me she is. She is like, a normal child to me [R: Mhm] Although I know that she's got a disability because like, she's not giving me that hard time [R: Mhm] It's only when she had a surgery. That's where I [R: Okay] struggle a lot because now she's in pain.

R: Okay.

M: But then, like, our life is normal. And it's like, like, I'm like I'm when I'm saying it's normal. Like I'm talking about the special times that we have. [R: Yeah] Like she's not giving that. She's not giving me that hard time. And she's like she's always willing to try.

R: Yeah.

M: Because like, I don't know, sometimes I put pressure on her because I want her to learn something. And like, she just goes with my rhythm. She just goes, (R: laughs) I don't know what…she's just a perfect child. Like, she's very amazing. She's very amazing, even here at school. Like, she's like, she's coping. [R: Yeah] ever since we came, she's improving day and day, you know?

R: Yeah.

M: So she is a wonderful child (R: laughs), and I can say, I'm so blessed to have her.

R: Aw that's beautiful.

M: Yeah

R: I love that. Uhm So, Ncebs, you mentioned that she is deaf blind. Tell me a little bit about that journey, how you found that out what that whole process was like, [M: mmm] for you.

M: So when, when I first found out that she won't be able to see again, because she was born with that, but I didn't know that. It's something that can be a permanent thing, you know. So when I found out that now she is completely blind [R: mmm]. It was very hard for me, I, I couldn't manage to accept the fact that she can't see [R: yeah] I kept on like, finding help from different like, different institutions different, like different. Like, I was also like [R: yeah], so in deep know [R: yeah], our culture, things like [R: okay], because like, I had that hope that if maybe I can do this, this can help. [R: okay] so it was really hard to accept that she cannot see, but then in the long run, I have accepted the fact that she can see. And I was willing to help her. Like to learn things, the basic things that she needs to do [R: hmm], I had to learn myself that I have to make a learn something because like, it was it was like I didn't know where to start, because I never experienced a new one, you know, like that. [R: Yeah]. So it was very hard, like, but we I kept pushing like finding ways, taking her to therapies, and all those kind of stuffs. But then we also found out that she cannot hear the audiologist said it's profound [R: hmm] hearing loss. One more thing to add. [R: Absolutely]. Ah, I can't say I like to have been…like I've been depressed or something. [R: Okay]. I can't say because like, the way I was handling everything, like, when I look at depression, and I look at my story [R: hmm], and my, like, my hard work. I think I have I have escaped it. It was the I don't know. But yes, I was stressed. But I don't know how. How did I handle everything like [R: yeah], but it was hard, but then I managed, like, to accept everything. That's okay. It's like this. Now, what's the way forward? Like [R: yeah] I don't know if it's a good thing. Like to take something and, and say, Okay, it's like this. Okay. Let me keep going. [R: Yeah a hundred percent] Yeah.

R: That's what it sounds like. [M: yes] So, what I'm hearing from you, as well as that will, from what you've said, is that you didn't get depressed when you heard about a new diagnosis or something difficult. You almost channeled it into research. [M: yes] You were like, Okay, this is the problem. What is it that's going to help?

M: Yes that's exactly what happened. I'm like, yo, okay, now there is something that is adding up from this thing that I, [R: hmm] I just have to now focus on that one. And I was like, yo, this is peak, and it's, it's gonna be hard for her, I need to be strong myself. Just for the sake of her, [R: yeah] because she doesn't have anyone except me. I just had those thoughts, that okay. Now she's deaf blind, and I'm the only one she's left with [R: yeah] because her dad is not is not in the picture. [R:Okay], so now if maybe I have to stress myself and not finding help [R: yeah], where she's going to get help? So I must be the one who's going to be strong enough to get help and talk to people and get some ideas.
[R: Yeah], yeah.

R: So Ncebs, you've mentioned a few things. And what you just said now that I want to ask you more about. So the first thing that you mentioned, was when you were finding out that she was blind. Can you tell me a little bit about what your pregnancy and what your birth looked like? And then when that realization happened for you.

M: okay, uhmm during my pregnancy period, like I didn't have any complications, like it was uhm. I think it was discharge that I remember [R: mhmm]. And it was cured at my local clinic, I told them that I've got this fluid that is coming out [R: okay of her eyes] no [R: for you?] during pregnancy [R: Okay got you]. They said, it's a normal thing. So it's a normal thing to happen, but it can be treated and then like they treated it [R: hmm]. I think it Yeah, I think it was an infection, though. I think it was an infection [R: okay]. But then it was only that. [R: yeah]. It happens that I remember that. Maybe it could be something related. I don't know. [R: hmm] but it was only that. And then. Yes, I was also sick. Like I was at that. At that time. I was like, I couldn't, I couldn't accept the fact that I was pregnant [R: okay] because I was supposed to go to school and at home we're not like, we are struggling with everything [R: hmm]. So I was the one that completed matric and I was the one that they hoped I would make a change at home. [R: yeah], so I was having that pressure [R: yeah], while pregnant that okay. I made a mistake. Maybe I shouldn't have taken that gap year. I may have, I should have, and they didn't have money to take me to the varsity. So it was stressing [R: yeah] me out during the pregnancy [R: Absolutely]. And then after, okay, things get well, they accepted that I was pregnant. They supported me very well.

R: So it was your stress and family stress? So you already stressed about being pregnant and then also the family were stress. Okay.

M: So then nine months full and then, no, it was not nine month. She was premature. [R: Okay], that's the eighth month. [R: Okay]. So then we went to the hospital, then I gave birth natural. [R: hmm], and uhm during during the delivery process, I can't really remember what really happened [R: hmm], because uhmm the doctor said like, it's too early for me to give it but now I was in pain. And I felt like something was coming. And then I gave birth during during the day. And then they gave me my child. And then I noticed that the eyes were big, [R: okay] like a big, huge. And then they were like, I asked them that's why at the eyes so big. And they said you also have big eyes. So what do you expect? This is your child [R: hmm], and I was like, okay, but she couldn't open the eyes. And then I they took us to the labor word. And then in the morning we were discharged. And then uhm after we were discharged, Aliza opened the eyes on … I think it was the third day? Second day? [R: it took her three days to open her eyes?] yes [R: okay], because she was like she was open that she was opening them [R: little bit?] yes but you couldn't see anything.

Because like their way like big [R: hmm]. And yeah. When you when you saw them tell that they were paining but since it's a newborn you don't know what happening [R: hmm] in the eyes like it was my first baby so I didn't know if they are like that when the baby is born or they are not. [R: yeah]. So then on six days, I was taking her to the clinic because they said I must take her to the clinic after six days just to check up [R: okay]. And then I took her and then I already noticed that the eyes were okay, she opened one eye on the on the third day and then on the fourth day she opened the other one. So they were grey, like, completely grey, like dark grey [R: okay]. And then I took her to the clinic and then at the clinic, they saw the eye, they said, you must take the child to the back to the hospital because the eyes are not okay. [R: mhm] and then other people says maybe it's a there's something called, what is it? I forgot now, but it's when you were eating too much oranges. [R: Okay], and then it happens. But then in the long run, it's just go away [R: Okay]. So they thought it something like that, people with their knowledge and then they said, I must take her back to the hospital, then I went to the hospital, I showed them that the eyes are like that, then they transferred us to another big hospital [R: okay]. And then from there, they said, they're going to do a surgery. But then they keep on rebooking saying, the baby's still small, the baby…they out of beds [R: hmm], like it's too far from my home. So I was really struggling [R: yeah] like to go there. And then get nothing and then come back. The baby is not getting any help. Then I asked them if are you going to do the surgery or not? They said, you must be patient. We're going to do the surgery once we have beds and stuff, and I told them that this thing is spreading. Because now it's been a month now [R: hmm]. I can see it spreading all over.

R: So Ncebs, you went to the clinic then at the hospital, you had to wait a month before they saw her?

M: So, no [R: no], they gave us a date because it normally gets full then in specific dates, [R: Okay], a date within the month, then we went to the hospital, then to the hospital. They gave us a date. I think it was uhm a week after, a week after, to go to that hospital. The big one. [R: Okay and then and then they kept delaying delaying]. Yes, that's what they did. And I ended up going to another one. There is another one in East London [R: mhm]. I went there because like I googled that there were specials… specialist for the eyes. [R: Okay], then when I went there, I don't know if it was a semi – private or what? They wanted to help me but then they were afraid that if they help Aliza, what about the hospitals that she was attending? They don't know what they have done to her. So it's gonna be unfair [R: oh] for her to start from scratch. They don't know what happened. Like they understand me when I tell them that, [R: yes], I really need like urgent help. They said it should be…it would be better if they gave us a transfer [E: okay] to that hospital. And I was like, they won't give me a transfer because they'll be like, they'll be feeling like they are failing to do what they're supposed to do [R: mhm]. And then, like also a walk in so they couldn't help me like that. [R: Okay], and then I started to Google here, the hospitals here in Durban. I found McCord. That's where I came. It was also a struggle even for my McCord to accept us. Because they were asking, what was the base hospitals what like what [R: they needed the feedback] yes, what happened to her, what they have done already up to here and like I had no like, more information because like they didn't do any surgery. They just went to the theater just to check what was the problem? And then they said it's called congenital glaucoma. That's what they said from Eastern Cape [R: okay] and so then I only had that, that information that what's the disease called [R: okay] was like nothing that they have already done, like surgeries and stuff.

R: And did they tell you when they said she's got congenital glaucoma? Do they tell you if there's anything that they could do to help or what that would look like for her? Did they like give you more information?

M: Yes, they said they're going to do a surgery [R: okay] to take that thing away? That's what they said to me.

R: And how long ago was this? This is when she was young?

M: Yes, think she was three months, four months by then [R: okay]. Then we came here when she was one year. [R: Okay], if I'm not mistaken yeah [R: okay]. Because Because she she she first had had her first surgery when she was one year [R: at McCords?] no, at Albert [Luthuli], [R:okay], so, when we got to Albert, they said it's beyond what they can manage to treat. So they said it's better if we go to Albert because they are more specialists there. So they just can't help her. [R: okay] so they transferred us right away. And then she was in Albert that's where she just started. They did the surgeries.

R: Okay. Okay. So how many surgeries that she had? [M: two] two, one when she was around one [M: mhm], and then? [M: the one and the other one] Okay. [M: I don't know, I can't remember if they're three or two]. Okay, [M: but there are more than one].

R: Ohh my goodness. So that was a lot of like, passing you along without actually helping. [M: Yeah] Aliza. It must have been very frustrating. [M: It was it was] okay. [M: But I was trying.] Yes, [M: trying]. And so the research you did was a lot of like Google the internet [M: yes] when you got a diagnosis also, onto Google.

M: Yes, I know everything you know about glaucoma like I, I Googled everything that they said, I even, like, I didn't even know that she's got also autism. So I kept on googling, and googling, and googling.

R: And when did you get? When did you find out about autism?

M: Hmm last year? I think it was last year. [R: Okay, so] but they didn't like diagnose her [R: Yeah]. Because like, I asked them, if they did diagnose her with autism, like, what are the signs that they are seeing? Maybe they are related. And then they told me about those signs that she's doing now. Like when she's angry and making weird sounds [R: hmm]. And like, tapping, like, repeat, like repeating, [R: hmm] repeating things like that. And I was like, how do you expect it like, it's normal? Because like, she's deaf blind how to? [R: hmm]. And then they were like, yeah, we do understand that, but they are more similar to the signs of autism.

R: And so, where was that discussion? Which doctors was that with?

M: KZN Children's Hospital

R: KZN children's hospital and was it was at the neuro paed [M: yes] or neuro? Okay. Sjoe Ncebs!

M: Like most of the children that are there in KZN Children's Hospital, they've got autism [R: okay]. And they, they just act like okay [R: okay], but to me, it wasn't easy to say. I'm not just like in denial. No, I'm not. [R:Yeah] , that I didn't understand if she is really autistic.

R: …because she doesn't have the vision or the hearing, you don't know what is also her exploring her environment using sound and touch and that kind of thing. Okay.

M: And those one can see can hear, but they still do the things [R: yeah]. This one cannot, he cannot see. But she also does those those weird things.

R: So what do you think?

M: I really don't know how to I don't want to lie. But she just acts like them. [R: Okay] that's all I can really say. She just acts like them. So it's possible for a doctor to say she's got it [R: Okay].

R: Okay [M: yeah]. Would you have thought about it before you went into that clinic? Did you ever think?

M: yes, yes, I thought about it, because the OT therapist that she's seeing. She asked if do you know about autism, something called Autism? And I was like, No, I don't know about that. And she explained to me [R: okay] about the child acts and all those stuffs and then I went to go to, I researched it and I saw, but then they like, and and, and what I also found out is that autism has to do like with mental problems.

R: So the brain development [M: yes] they didn't do the brain scan to her. So that's why I am not convinced that she is maybe if they have done it then showed me that okay, there's something wrong with her [R: hmm]. So I would understand.

R: So autism is also a tricky one. Uhm the OT is Kate? [M: Yes, yes]. Yeah. I'm sure Kate did explain but that but that it's not something that you can like, tell easily. You have to have difficulties in this area. This area in this area. It's like behavior, communication, something else. [M: yes, yes] so that's probably why they're going on without the brain information. [M: Oh] but I hear what you are saying cause there's no way to say [M: yes], for sure she understands.

M: Because I think she also took it from the from communication [R: hmm] and all this stuff because she just had to like, I don't know, she'll be not participating or not listening. [R: Okay], or not following the instructions that were giving her [R: yeah], I think it also comes from those aspects that she was not communicating well [R: okay].

R: Okay Ncebs, so that was the medical side, very complicated [M: yeah]. Very difficult to navigate, you basically had to do it on your own [M: yes]. I also want to touch on something you mentioned, when you first found out about her diagnosis, you mentioned a cultural aspect for you [M: yes], would you mind telling me about that?

M: Okay, it started uhh with because, like me as black people, we believe in ancestors [R: hmm]. So, in my family, I first went to a sangoma. He told me that my mom, my late mom is not happy that I'm pregnant. So that's [R: okay], that when Aliza was born, so my mother punished me through Aliza [R: okay], well, what I did, so she was, okay, they were okay. As they as they are my ancestors [R: hmm]. So they were not happy about what I did. So they were cool ones and they were angry ones [R: Okay]. So the angry ones didn't want even to come to the game. And then the other ones, like, they were like, okay, let's give it even if we give it let's give a with this disability at least [R: okay], but she must be, you know. So that's how, [R: okay], it happened. And then I was like, how cruel is that? [R: hmm] You know what, I'm just going to go to the grave and ask mum, how can you do such a thing? To me? [R: mhm] It's like, how can you give me such pain? And then the sangoma said, no, you have to do like, a ceremony, and I apologized to him for what we have done. And then I did, but like, I don't want to lie. I was not on that. Because like, I was having that thing [R: yeah] in my mind. Like, how could she do that? It's like, [R: yeah], if she is really my mother, how could she do something like that? You see him? And then after I've done those things, like things just get worse [R: hmm], after I've done those things. And I've decided to like okay, let me stop. Let me just focus on getting because even to the hospitals, like they'll just get irritated when we get there. They'll be like, okay, wait here. The moment we are out of beds, we can't admit you don't have done all you know, if you just okay and then the other thing is, after I've apologized and all these things, the sangoma told me that mum will come to me and say, I forgive you [R: okay]. And then things will come [R: in a dream or a vision?] in a dream and she never came [R: Okay].

M: then I kept on digging. Then I went to her father's house. And then I asked them, is there anyone or from the grannies? Who had like a problem like this? Maybe it could be the problem and then they said, no, they have never had anyone with blindness [R: Okay]. I moved to that one. And then they said, okay, it was something that it was a witchcraft [R: okay, just the same sangoma or this the gogo's?] when a sangoma says, I do the thing, but it's if it's not working, I don't go back [R: okay], I move to another one [R: Okay]. And then [R: I understand] and the other one said, this child has to go to to be a sangoma. She needs to be a sangoma. That's why it's just like this. The ancestors are on her shoulders. They're fighting with her. So the other ones they want her and then the other ones they want. And I was like, what's going on here? [R: yeah], these people are fighting with me. Because now if they want the child, they must take the child like not to let her suffer like that. And then he said, you know what, we have to pay for a cow. I need to do that. And those things were very expensive. I couldn't even afford to do them. And I was like, okay, otherwise they said otherwise if I don't do them, she's gonna die. [R: Oh, wow!]

M: Okay, I think that's where I got stressed when I look at her, and I'm like, Aliza, do you want to be a sangoma? Aliza will just look at me. And like it was, it was, I don't know how to put it, but it was a lot for me like to take and go step by step because like, it's our culture. So I also have like, I don't have to ignore them. Because I don't know, they might think they can be right, they can be wrong, I don't know. But then I like I don't give up on finding help to the people that know are alive because those ones that my ancestors they're just giving me like, more and more and more and more. So I kept on like, getting some help from people. People said just focus to your child and get her school and get it. If those those people wants to help you, they'll help you along the way. Just keep going. Because now you see you just spent, you just get the grant and then you go to sangoma, you give this Sangoma a whole lot of money.

And then you told you that the ancestors are like this, that says like that. So like I ended up saying, okay, you know, now I'm going back to church, I want the pastors to put hands now, it must be God who's going to control [R: hm] everything, it must be him who's going to choose if she, she, she, he wants it, she wants her to be alive or not [R: hmm]. When I went to church, unfortunately, the church didn't work, even to like, I was praying, and they were praying for her [R: hmm]. I like I felt like even those pastors of my church [R: hmm], they are very slow. I wanted like a miracle, like, (M: snaps fingers) fast one [R: to be healed]. People say, you know what, that church of yours is just slow. They are pastors that I know, they'll just put a hand on her, your child would see and I went there [R: yeah]. They wanted money. I had to put money [R: oh wow!], I want my child to be healed. Yo, it was a disaster! Even you well, even when I was in Durban, I went like almost 10 pastors. But at the end of the day, I didn't get [R: andthey all wanted money for the miracle?] yes.

M: You must give not for God to give. [R: Wow!] So it was like that, but then I ended up like, I taught myself that yo, this is like taking all of my time, is taking all of my energy, taking all of my money. I must just sit back and see what happens. And if it goes, if I get the help, thank you God. If I'm not I'm not, I just beg. Keep sharing my story to people. [R: Yeah]. Like that's how I ended up hmm…finding my own way of living without listening to someone else. If this child needs that the child needs that I just I just stopped everything and then I just focused on her, okay, what are we going to eat tonight? As long as we have food today. Then we'll see tomorrow what we're doing. Because now what was happening? I was financially broken, emotionally, physically. And I couldn't buy even…because now I'm busy chasing what other people saying what [R: yeah]. What what they say it must be done and it's not still not working. That's where I stopped and I took it to her therapies [R: hmm] and like, things get better and better and better if I find people helping me. That's how I stopped, no, in that. In that Department of cultural. I just stopped [R: okay] in order to escape it [R: okay]. I stopped and I kept on taking care of my child [R: yeah]. Like Like I can afford, [R: okay], then I I made sure I made sure that she's okay. With what I have. I gave her what I afforded [R: okay] that's where.

R: So you work with what you have [M: yes] okay, long time to get there [M: yes] (laughs) [M: It was like], yeah, [M: a long time]. Yeah.

R: Okay. Thank you for sharing Ncebs. So you have mentioned in different stages of your life, that there have been people there that have been advising you telling you, that trying to give you advice. [M: hmm] Who were those people? So you mentioned at one point uhm when you were on your search [M: hmm], and you went to her dad's family, all of that there were people that told you just go with it to see where you end up even now, when you got to Durban you mentioned that there were people helping you. Who were those people? How did they come into your life?

M: I think they were sent by God. It's only the strangers that are helping me. Like, [R: okay], like it's only this thing. I never got help from my friends, my family. I never got support from those people. It was the strangers, the people that don't know me. So that's why I'm saying I just stopped everything. And God, He was kept on giving me people that I don't know. And like they were doing. Like, huge, they would give me huge help. That I couldn't even say thank you and who are you? [R: hmm]. So it was always strangers even now.

The people that are helping me is people that I don't know, or it's the people that you see, you are you are also a stranger because you don't know me, you not related to me, so what I'm trying to say it's not the people that I was close to [R: yeah]. It's not the people that I was hoping maybe one day they will help me so [R: yeah, just people you meet along the way?]. It's the public. [R: Okay], yeah, yeah. [R: Okay].

R: Do you need to take a break Ncebs? [M: No, I'm fine], you're fine? Uhm (takes a breath) okay, so Ncebs, I want to ask you a little bit about what it means for you. And for Aliza, in terms of feeling like you belong somewhere. So it doesn't have to be a specific place. But when I'm talking about belonging as a whole, I'm talking about where is it that you can go where you feel like you can just be yourself where Aliza can just be herself where you get to (breathes out). Breathe out, relax, when she gets to be whoever she is, when you feel like you're not getting judgment. Is there a place that exists for you? Or are there people when you're with them, you feel relaxed? Because you feel like they understand me they understand Aliza and we just get to be who we are.

M: It's Khanyisa, it is Khanyisa and she's also like she also went to other schools in Musgrave, there was a school that called it is called Bright Eyes in Musgrave she also went there. It's a wonderful, it's a wonderful place like it's like Khanyisa. Even though the teachers they like they were very nice they were very helping me [R: hmm] like everything like so so far it's it's it's it's those two education schools and those love from those schools like here in Khanyisa, like the people that are working here like when I'm here like I got like I even like when we were on holidays I even remember that break that I took (R: laughs) five minutes because like I'm with her like full time so that's where like I got to to find myself and … [R: to let go for a little bit] yeah because I can't say at home. At home I think about okay what I'm going to cook up and Aliza is busy you see even in my environment like it's not a good environment for us but we just don't have a choice because we are too close to our, we, am close to Aliza's services [R: okay]. It's where I can easily reach. [R: Okay], her hospitals. It's even easy to come to school. Also, so I can't just I can't even say where I live. It's where I found peace [R: hmm]. There is no peace even where I stayed there. Like, even people there. There's a lot of violence.

R: And where do stay Ncebs?

M: By Umgeni Road. [R: Okay]. So it's an informal settlement [R: okay]. So I can't say it's it's a place to say [R: yeah]. If I if I take you to the park [R: hmm], that's where also like I feel I also feel safe because the parks are around those those houses for people that [R: okay] yeah. So so like there it's safe and like you can that's you where you, it's where you I meet people that I don't know. And then they'll just start chatting and then I'll be like, relief from everything. And Aliza is just playing. Just playing there. And then I got relieved [R: yeah]. Yeah. So this is like that.

R: Okay. So people, places are almost where there are other people for you to connect with [M: yes]. We feel like, okay, it's not just me and her [M: yes] someone is asking a question about my life or something like that. Okay. [M: Yeah]. Okay. So that's what it looks like for you? When you feel like you belong somewhere? [M: yes] Okay. So Ncebs, can I ask you then what, what does what does community mean to you?

M: Yoh community? That is uhm, I can't even like, put it in a decent way [R: hmm]. But they are. They are everything to me [R: okay]. You know, sometimes I just bump into a person and I don't know, what's her problem? And then I'll be like, okay, can you please pass me that? And it should be like, excited to do that. And I'm like, on my mind, I know how hard to do that. Maybe okay, can you please grab that bag for me? When maybe I'm taking your tickets or something? And like, they'll be willing to help. So like, for me community is? Like, I don't know, I don't know if I, if they make me like to? To be to, to, to want to be one of them. I don't know how because like, it's not everyone that is willing to help. But I don't know how, how to? How can I be those ones? That have been so good to me? I think and I think it's maybe 90% of them. And then the others I think they don't understand because like, I'm not even paying attention to those ones, like maybe going somewhere and then they'll start gossiping and saying, oh, look at that, you know, all this. I'm not paying attention to that. That's why it's not even worrying me. So the community is like, to me, it's, it's, it's the people that I have from where I was to where I am, it's because of them. Like, [R: okay], yeah.

R: and that's a whole lot of people that some people you know [M: yes], some you know, some people you meet in a taxi [M: yes], some people that work at places where Aliza goes often?

M: Yes, it's those people that I meet and then I have like an ongoing relationship with them. And yeah.

R: Okay. And so let's talk a little bit about Kanyisa. When did you start? [M: this this year], this year, [M: I can't remember the month] and, and in Kanyisa and bright eyes. What do you think it was about the environment that made you feel good? Or that made you feel relaxed?

M: Yo, they gave my child love. They give my child uhm, yo, even they were helping my child, even me as a mom, because like, I couldn't cope with her in terms of how do we communicate at home? How do I make other people to understand because other people need to learn from me [R: hmm] how my child behaves, I need to warn people if there is something maybe or maybe I want to warn them that okay, Aliza is like this. So I must give you that idea of how to expect from her from her, and how to, to build relationship with them, like most of the people like that, now she's got relationship with, and I thought I'll be the only one who will be able to touch her to, to make to make to dress her, to make her to do anything, but now, there is a lot of development [R: okay] from from what I have learned from both of, of these schools, like I didn't even know how to tell someone that okay, Aliza is got this and that. So you have to be like this in order if you want her to do this. So like, they helped me as a mother, they helped her as a student. Like there is a lot like they, they have given her love. And they also gave me hope [R: okay], in a way, because, like, I sometimes you just believe that, okay, something is going to happen. But then if there's someone who's telling you now, but no, it's going to be okay. Like, it just changes how I see things. Just to tell me that's no, everything's going to be okay. We also have children's like this. And this helped. This helped. That helped. If you can do this, we think it's gonna help we can try this. We can try that. Like it's giving me like, like more, more power to say, okay, you know what, I'm also going to try my best, even if it's a hopeless situation, I can see. Okay, like when I got here in Kanyisa, or like she was not walking. And I was like, yo, what if maybe she ended up she ended up in we're in a wheelchair. But as I as as the staff here, in khanyisa telling me that, no, Aliza can work, we can see that. And you'll be like, yo, you can't even see that. But they kept on saying the same thing. And like, Okay, how about today we try this. And now you and I'm also like getting that, okay, maybe maybe it's going to help now. It's changing the way I think now the way I see things.

So like the ideas and everything that they have given us. It also changed the atmosphere. [R: okay]. Yeah.

R: I understand. Good thing to have some hope [M: yes]. After everything you've been through. Okay. Um, then Ncebs, and then tell me what, what is your dream for Aliza?

M: Uh for her to be a big girl (R: laughs) she's also a big girl. Like to, like so far, like, I feel like, like, my dreams are already like, achieved. Because like, yoh, like, what I'm trying to say now. I think the things like I getting lights lighting up. [R: Okay]. Because, at first, I had a dream that okay. If she can walk, if she can stand if she can open her mouth just even if she's not saying mama, what if just like those things, but now as she is growing, I'm seeing like, day and day improvement. [R: Okay], so now to me, I don't know. That's why I'm saying now our life is like a normal life because like she's not that [R: hmm] troubling me. You know, like when when when I when I chat with other moms maybe at hospitals when you share stories like I would hear that, yo, some other mom moms are struggling because like they are children. Like they are not controllable. Because and then I'll just compare the stories as we're chatting in that like, Aliza is not it is not troubling me that much. It's just that maybe it's it's, emotional feeling [R: yeah], sometimes when I get that okay, no oh, she's like that and but she is not giving me a hard time. I don't wanna lie. I don't know as much as she goes, she's becoming 18. I don't know about that (R: laughs). I don't know about that. But I can't say she is troubling me that much. [R: okay, but, you know, just take it day by day]. Yes, yes. Yes. And like, like, I'm just saying things going fine. Like, I'm not. I'm not having that thing that okay, now. I wish my child could like this, because now I have accepted that she's got these disabilities. Now I'm just, I'm just looking for what can help this now. What what's the way forward to help her to do that. [R: What's the next step?]. What's the next step to take?

R: Okay so Ncebs, when you're out in the environment, when you're out, get trying to catch a taxi when you're out in the world. Is there anything that you can think of? That you sometimes are like, oh, I wish things were different? Because then if they did it this way, it'd be easier for Aliza or it would be easier for me as a mom, are there things that you can think of? Like?

M: I think if people can, like, get educated about how people with disability live, like, because it's not, it's not. It's not only us here in Kanyisa, understand, Aliza. I'm just making use of an exaple, [R: yeah, yeah] it's not it's not only like, it's, it's not only you guys that understand that, okay. Aliza, if she's crying, if she's screaming, if she's making this, okay, I understand it might be triggered by something, you know, not all of us understand that. So I just wish people would get educated about those kinds of disabilities, just to know that if someone is disabled, don't expect that someone to act like she is, or he does that thing intentional [R: okay]. Because, like, we want what people know about people, people with disabilities, that they'll just feel shame and oh shame, they can't do anything for themselves. Or shame, maybe they need food. Or they like that's, that's all they, they, they they can see. But they don't have, when they don't have experience, they don't know how to handle those situations, if they meet those people. Let me make an example. If you know that a blind person cannot cross the road by himself [R: hmm], then he needs someone to help. The only thing you know, is that, okay, I have to help that person, you don't know the feeling that person is feeling. Because you see, now you just come to grab him and say, let's cross the road. That person first of all, doesn't trust you. And he is he is even scared to be outside [R: hmm].

From the people that are like, from too many people. And like he's like, the way they they feel, I wish they can feel what they feel. Because now I have a better understanding since I have Aliza. So I just sometimes feel what Aliza feels. Sometimes I'm not saying in all the time, but sometimes I do feel Aliza's like emotional feelings. I wish they can understand that. It's not always that if you go to school, and you got trained, now you know everything. Like I think they have to look deeper on how they live, they they have to understand their environment, their world [R: yeah], they don't know their world, how are they coping with everything. At the end of the day, they can't be be looked in some way and say those are the disability ones. They must live at their own world, they still need us as a as a community. So I think if they can learn more about how people with disability live, they can understand better than they can treat them better.

R: And know how to include them.

M: Yes, yes. Because even the children, they they, the children doesn't say strange and strange things to other to other people with disability, they hear from the society what other people saying [R: yeah], and they then they copy from that and say that if they're calling Aliza a monster. They don't know. I'm sure, they, they, they have better questions that they should ask, and why are her eyes like that, but for the fact that they already know that she is called a monster, they are going to just say straight away, okay, this is a monster, come and see, there is a monster there. But if you educate your children, and you let them even the society to know that no, a person with eyes like that, it's not like she's a monster, she can walk, she can eat, she can do things like but you have to treat her in a special way. That's why they're saying they need a special needs [R: yeah]. So you have to treat it in a different way than the way you treat the normal person. So I think if they can get like knowledge on how to treat them and yeah.

R: And Ncebs, has somebody called her monster before?

M: Yes, [R: children?] was the children but I understood to because they, the mom came to explain to me why she did that [R: okay] it was from other people, not from, [R: adults? Other adults?] adults [R: So other adults called her that?] yes. [R: and they taught the children that]. I was not there and Aliza was not there so they were just talking without knowing that the child was. So the child just called him with what she heard. [R: Okay], that was said.

R: Okay, and so those so the, do you think that the adults called her that then the childhood that and then called her that? [M: hmm] And did those adults come talk to you about Aliza? [M: no]. No, do you know who they were?

M: Yes, I knew them. Yeah, I knew them. But like, I never took it personnel [R: okay], because like, I know, I know, even, like, that's why I'm so easily to understand this because even my own family didn't understand. I didn't like felt that, okay. Now, it was the it was, it was for the first time, like in my family to have someone with disability. So I think it was hard for them, but not in a way that they can be, like, distant they can be that distancing themselves, you know, because they even say, you know what, you can just bring Aliza with us we will stay with her just continue. [R: Okay]. That the schooling because we know how our situation is, [R: yeah]. But then I couldn't let her to stay with them. [R: yeah]. Because like, I knew, like, I used to see, like children with disability.

They just get worse and worse and worse, especially in our areas. Because like, if a child can't walk in, they don't go to therapists, they don't go to any day. They just gave them a wheelchair. And then that's the end of their life. They'll just stuck there forever. [R: yeah], So like, I imagined her, like, I didn't know she was capable of walking, or making sound or eating all that. But like, I just knew that if I let her with them, she's gonna end up like that like worse [R: okay]. So that's why I refuse the left side. I'm really sorry that I chose my child. Over like everything. I know that I promised you that once I completed my matric, I'll make you proud. I'll go to schooling. But then now, I can't. I can't [R: yeah]. Now because I know you've also got like, one person got four children, other ones got five. So how are they going to manage to look after her, and they were like, no, it's fine. And I was like, no, it's not fine. It can be fine. So that's where I had to like, make a decision and choose and choose [R: choose Aliza or choose your family?] Yes, I had to choose Aliza over my family, I had to face the consequences of that. Because like, obviously if I choose her, I have to be on my own. I have to be on my own like they can't do anything because they gave me a choice but give us the child and then but then I chose not to.

R: And what is your relationship with them now Ncebs? Do you talk to them?

M: Yes. [R: Okay], like, they are fine. And that's why I'm saying, it's just that with us, as mothers, to love them, to give them to give them the best that we can in order for other people to do the same. Because even those people that were calling her a monster, I'm sure they they never called her again, because they saw what I am doing to my child. So they called her a monster but not treating her as a monster. So I think they also learned from that that, okay, we can call it that. But the way her mom is treating she's treating her like a princess (R: laughs), just treating it like the best thing ever in the world [R: 100%]. I'm sure that change also changed their way of thinking like, okay.

R: So you always make sure that you treat Aliza the way that you think other people should treat her so they can learn from you?

M: Yes, yes, I think I think that's one of the points that I should have added from what can the community be like, is just treat them the way that they as they can also do?

R: Treat them how you would want to be treated? [M: Yeah]. 100%.

M: Because that's, [R: yeah, yeah] there is that inequality. [R: Yeah]. You just experience sometimes. Yeah. Okay. What was that? Okay. When people and then it like, okay, can their child their children, then they'll be like, okay, can we take your child to that side? And then when, when the other child she was playing with her, try as follows and then they'd be like, no, not you only that, one must go that side. You must go to the side. And then you just observe everything and like. Okay. There is inequality. Okay, now, this one is just disabled, she can’t play with the normal one. Or maybe they think there must be something that can affect the normal one. And you can even you can even find being discriminated like, even in stores. Because the other day, I used to take Aliza to the malls. [R: yeah] yeah. We had. [R: Okay, yeah]. [R: Maybe 10 more minutes? Yeah.]

M: Thank you. And then you that's, that's where like, we see those things in malls. Because the other day, I took her to the mall. And she like she makes those sounds. So she wanted to, like, look at them like Aliza was moving around, she couldn't see clearly. So she she followed us and I saw her that she was following us. She left her parents (R: laughs) on the other shelves, following us. And then I look into it. And I was like Hi! Do you want to come and see the baby? And she was like, no. okay, I carried on. [R: Yeah]. But she kept on following us. [R: Okay]. Okay. Then I turned back again. And I was like, where is your mom. Then she was not talking about she was just pointing. [R: Yeah]. Okay. I said, okay, like I was a little bit irritated. Because like, she's following us and she's not like, at least if she said, yes, I want to her. I understand them because it's very hard for them to just say, okay, she's blind. Okay. I understand. They just want more of that. Even. I even like, talk to them and tell them if even if their moms are like, no, don't look, don't look. And I'm like, no, you can let her look. And then I'll tell her. No, she's different. She can't hear you. She can't see you. And then they'll be like more interested in oh my god, what happened to her? She was born like this. Oh my God, I don't wish to be like her and like she didn't choose to be like this even her and they'll be like, really?? (R: laughs). And that like, yeah, you know, like I I do my part to educate even those ones because they don't understand. [R: Yeah], so that one just came and then, okay, and then I went to the till to pay. While we were there she called her mom, grabbed her, like it. Like, to her it was like maybe I did something to her, or I call her something. And then she came. She was like this lady. What did she do? She was like the baby. Yes, the baby. And then Aliza was on the trolley. Like, the lady was confused. And like, I didn't want to tell you what really happened. Just stood in the line. She grabbed her say, the baby is this. I don't know if she's like that. Oh, they said what I don't know. [R: Yeah]. And then Aliza was making the noise. And then they said he was making that noise. And the line was so long. I was like, okay. Do I walk out from the store or do I stay? Now they start to talk about her making the noise. [R: Yeah]. Like, they didn't see how it should be. [R: Yeah]. And then the other one said, no, the baby's not okay. She's okay, I think. But the lady was like, so. So why is she making so much noise? And my, my, my daughter now is scared of that. And he's, he's not feeling any comfortable? Or maybe I must leave those things and go out and wait her to come out.

R: What did you do? Did you stay?

M: And then the cashier, the assistant, the one who's assisting was listening to the conversation. And then you told the manager, then the manager came in tells, like, what happens? No, I'm just going to leave this bucket, this basket here. Because now this child is making my child to be uncomfortable. You also have got rights as customers. But we can't just be here and be and feel uncomfortable. But I just I can just leave. And then I was like, okay, let me just leave them. And so it's not because even the manager is not like [R: he's not helping you]. No, no, he is definitely not. Like who's that? Who's that? and then they kept on pointing me and people are looking and yeah, [R: became a whole thing].

R: Did you stay or did you go? [M: I went out] and you left your groceries?

M: Yes. I went out and then I waited for them to come back to come out. But as I was out, I got like angry and I was like okay, let me just not get in back. Let me just and then you know, the mall is too small. Then I went to another shop and I I met I bumped to them again. Now we on the line to ATM. I was going to ask for cash back inside. [R: Yeah]. And bought my things and then go [R: okay] now I had to the ATM because [R: yeah], some other stores were full.

And then were they standing ayh the child pointed and shouted and screamed, blocking her ears. I ended up just going out from the mall. That ruined my day.

R: Did this happen recently Ncebs? [M: No, it was long time ago. Aliza was not] but you still remember? [M: Yes, I still remember it] so clearly.

M: Aliza still even younger. [R: was this in Durban?] Yeah, here. One of the malls, but most of the people that buys they are people that got money. So I went there to buy Aliza's toy anyways, from one of the stores that sells toys, so someone recommended a toy, and then gave me the name of the store. That's how I went to that shop. [R: Okay.] Yeah. So people sometimes they don't understand that. We, as mothers, can you imagine if Aliza was hearing all those things? [R: Yeah], all those names that they called her how maybe she would be [R: 100%]. So we just need to be strong as as the ones who are taking care of them and be strong for them. And always like, find a way out. Not to cause trouble to anyone. But I'm sure as time goes on, those people will like recall and see that that was wrong. [R: Yeah], but the stuff that they didn't have knowledge. Like they I don't know. I don't know because like, I do understand the part of the child but for her mom to be like that, too.

R: Yeah. And for the managers even of that shop [M: yes] to not want to support you either.

M: Yeah, so things like that happen. Yeah, we've been through a lot. [R: Yeah. Absolutely!]. So that we can't just keep them indoors and say, okay, now you're disabled. You can't go. She needs to like experience get used to people [R: Absolutely].

R: So do you take her now to the malls? Or do you not?

M: I do [R: you do?] I do. I just, I just don't mind people. That's why I'm so okay. It's it up? And it ended up to just say, okay, let go it just, it just like, just pains. Just the moment it's happening. [R: Yeah]. After, like, you're so now whenever I'm disappointed from somewhere, I won't go any give any any more because of one, one person or one? People. So I just have to keep on the, and, if I'm like, I'm taking her to a mall. And then I found the same problem. I'll just find another option. Another. Like, I'm like that. I'm always like, looking for new things. [R: Yeah]. If it's not working, okay, it's fine. [R: Then on to the next thing] on to the next thing. Yeah. Yeah.

R: Okay. Amazing. Ncebs, thank you so much for sharing with me. I really appreciate it. You spoke about some heavy things (R: laughs) [M: yes]. I just wanted to say thank you for your time and for being so brave and vulnerable. It's really amazing to hear your story and to hear how much you've been through and how much you fought for Aliza, for her to be where she is now. You really are an amazing woman. I hope you know.

M: Yes, everybody tells me (R: laughs) like it's something that's now I have taken it as a as a reward. I can say like, whenever, like, I go everywhere like people just tell me the same story. So now it's it's it has become like my reality. That yes, you are like that. Even if before I was not trusting myself, if I can do it all. But now I just like as much as you telling me that you are strong. You are amazing. Like it just boosts my energy to keep going. [R: Yeah, it's good to have that affirmation that use]. Thank you so much.

R: You’re welcome.

Transcript of Interview with DaCanha's

Codes	R= Researcher	M = Mother	F = Father
	(text)= description	[text] = adds a word in	*Text*= emphasis

Background:

I met Tate and the DaCanha's in 2017. They were a family in search of answers and a family on the hunt for help. They had tried so many avenues and they kept coming up short. There was so much going on in their lives at the time that for the most part, it all feels like a blur. Tate was an incredibly frustrated little boy. So frustrated that management decided it was okay to break the rules of therapy only happening in the classroom so he could have some one-on-one support. He was a tiny tempest who did not take kindly to being wrangled for his weekly sessions but all at once, he exploded into life once he found the key to unlock his communication. I have maintained a therapeutic relationship with the family up until 2023. It was a wonderful evolution for us all.

Tate is such a vibrant and energetic young man. He loves practical jokes and has aspirations of being a YouTuber. He has loved transportation since he was 2 years old and this is a love that has endured. Tate is now verbal and has so much to say. He is loud and loving and a source of pride to his family and his teachers.

The family was contacted verbally to participate in the study. Once initial consent was obtained, the interview was then scheduled via WhatsApp. The interview took place in person at their home with mum and dad in attendance. Tate was present in the next room during the interview watching videos on YouTube and he pops in and out of the interview at various moments. We sat on the patio on a muggy Durban evening. There was the occasional car driving by but for the most part it was just the soft patter of rain and the gentle rumbles of thunder. How fitting a night for Jono and Debs to share their story. Parents were given a bit more background to the study and the researcher clearly explained the difference in relationship for the purpose of the interview (i.e. Therapist vs Researcher). The interview took place as follows:

R: Tell me your five year life plan. Okay, perfect. This is working. All right, Debbie, Johnno. Thank you for agreeing to my interview [M: you're welcome]. And so essentially, I am. So I'm doing my PhD. And I want to look at community practice. And what that looks like for SLT. So very often, what my job is, is working with a family, and then we come up with something that helps the child like uhm AAC, which is our alternative communication. And then the burden is on the family to keep going with that communication. And what happens is, we work on that and it's amazing, and the child is communicating. But then they go to a shop, or they go to the beach, or they go somewhere with that method of communication is not always understood. And like, I have incredible access to stories of families like you guys and the Northends who have experienced this firsthand.

And it's really like made me think outside the box in terms of what we can provide as STS because sometimes I think we're quite limited. So I would love to look at how we can shift the burden from just being on the kids and the families to empowering communities and helping them understand uhm

what they can do to make sure that our kids are included. So I just have some questions. There is nothing like there's nothing specifically SLT related, it's more just about your experience of community. So you just jump in whenever there's like a super hectic structure. [M: am I gonna cry?] you might (R: laughs). But nothing you say right or wrong. It's just your experience. So we'll start off with a little bit of an easy one. So tell me about your family.

F: Okay, so, that means I'll go first (R: laughs) So, Debs and I we've been married for 18 years? 13 years. And two kids. We had our kids pretty close together. Uhm not intentionally. Our first daughter was in… our daughter was intentional. And then we wanted to have another child quite soon. But it happened to that it was what I think nine months later, [M: Hannah was four months]. Hannah was four months old and it was four months old when we found out that then I was I think three months pregnant or something like that. So they ended up literally one year apart. So both of them have birthdays in November. So, So yeah, it's just that four of us. Smallish family. What else do you want to know?

R: Uhm tell me about what Hannah. Tell me about Tate.

F: So had Hannah is awesome. Tate is awesome. Hannah is a, loves dancing. Very specific, very pedantic about knows what she wants and how it must be. Very kind of strong willed in that regard. And super fun. Yeah, and Tate …

Tate hearing his name comes out to show me a video he had taken of a storm in slow motion. He has managed to capture beautiful flashes of lightning"

R: That was actually very amazing. That was amazing.

F: Yeah slow motion. He waited. He makes me hold the phone forever (R: laughs). I couldn't get it if he forgot about it. And then he ran it. I got it. So anyway, yeah. So I Tate's also awesome. He's on the autism spectrum. And we found out when he was about two and a halfish. Uhm and he was diagnosed. And amazingly, what I found with him is that although he's on the autism spectrum, and that he is very uniquely autistic in that he's very social, very vocal, very, sort of interactive and boisterous and doesn't mind noise and things like that, which is not common for autism. Uhm so yeah, so I mean, he wants to go wingsuit flying, and he wants to go skydiving, and you want to surf and you want to do all these things, but you have to keep telling him when he's 18. (R: laughs) okay, so yeah.

R: Beautiful. Thank you. And then can you say a little bit about the journey of getting a diagnosis?

M: Okay, the journey of finding out. So we, he spoke a few words 'Hello', 'dad' 'Han' I think. And then he stopped. And then which is typical but of autism, but we, and then at school play school, he wasn't really interacting with the kids he was kind of just sniffing his blankie doing his own thing. And he always wanted to climb and he was moaning a lot. Anyway, we knew something wasn't right. And then I saw an article, and it was about autism. And there was little boy lining up his cars looking at them. And you look, and he looked just like Tate. And I showed Johnno and I said, look, I think he's autism. So we went to the Lyn Campbell, and she did an assessment uhmm and then told us yes he's on the spectrum. Then my world fell apart pretty much because you like oh my gosh what does this actually mean? What does the future look like? You think about all these kinds of things.

F: It's the last thing in your mind. Not even in something, maybe it's auditory. Maybe it's…we actually thought he was auditory at first. Sorry to cut in. But we thought maybe we thought it was he had like, what's a glue ear? We're like you're not hearing properly. So he wasn't talking. You'd like clap your hands and he wouldn't respond. So we were like, what's going on there? Autism was not in our mind. Uhm so when the diagnosis came, it made a lot of sense. But we had to like quickly, deep dive into what is what is autism? I mean, all you all we really knew is what you've seen on news. And you know, the stories you've heard of it, but we didn't know a lot. So that's quite a quite a shock.

M: I think also, we have because we've had this had them so close together. It's like the milestones and what Hannah does, and then he's not doing it. It's quite, it's not like you've got four years difference. It was quite a shock. It's like having two young babies, but one is very different. So that was hard, but luckily, I got hold of Sarah Araujo. And I spoke to her and then find out.

R: Did you know her?

M: I knew her, we were in the antenatal class together. So when I was pregnant with Han, and she was pregnant, so I knew her from then ago. So when I spoke to Sah about it, she's like, oh, my gosh, Khanyisa. Anyway, so I think the first few years of autism was just absolute [F: chaos] hell. It was so hard. I was also not well. So my journey of autism was more straining on me because I wasn't well, that also it was just difficult he wouldn't speak, he was non-verbal. And it was communication was hard. And dealing with two young kids was hard, trying to show Hannah love and attention when your brother screaming at night. And that's why Jono did audiobooks. But I think that whole. That whole time was just absolute mess.

F: Yeah and the fact you're dealing with two babies that are entirely dependent, but they're different milestones or are different, like a year apart? So one is having non-solid foods, that both nappies, one starting to sleep through and ones not sleeping through at all. And so you like, what, two, three years we like, lost a lot of sleep and all of that kind of stuff. And then it was difficult to give Hannah attention because Tate was so demanding. Bedtime his demanding, morning time his demanding to do everything for.
So it was all of that that's kind of like a culture shock. It's like a family shock. And so it's like a personal shock that you have to kind of get through.

M: I think also for us, we had a like uhm they both had issues with tonsils. So from a young age, rushing to casualty at three in the morning [R: gosh]. Honestly, there still be issues in the hospital because we were literally every three months whether it was with Tate or with Hannah, sometimes both at the same time. In fact, Hannah was in hospital while I was pregnant with Tate. And then we didn't know about Tatum autism in the hospital, but he was always busy. But he was such a charmer. He would like give like looks to the nurses like little lap looks, you know, such a charmer. We had no idea about autism. And it's funny because I think back and I go gosh, if I hadn't known he had autism, I would be more anxious in the hospital, but I just took it as he's a busy kid. And he's a boy, you know, those kinds of things. But I think that was also quite hard as being in and out of hospital with them both uhm that was quite hectic. But I think adjusting to autism for me as an acceptance. I only really accepted at about four years ago. When I worked at Kanyisa. Prior that I was like, I hate autism. I'm not accepting, not denial. It's more like hurt. That that's the future of my my son. Yeah, so yeah.

R: And what what was the change for you in accepting?

M: (clears throat), I think it was realizing that it's not so bad. Like, I'm around kids on the spectrum all day. And I see the severity of them. I see how hard it is for like, Angela and Jason. And I think of, their life. And I'm like, oh, my gosh, Tate is *so* much better. He's just progressed so much. I'm so blessed. So now I've looked at it as I'm actually quite blessed to have him not that I wasn't blessed. But I just wasn't blessed by the autism. Do you know what I'm saying? [R: Yes]. So I'm not accepting. Also, what do I want him to have a future and I want him to be a re…, you know, miraculously healed, whatever. But the reality is, I'm accepting that he is the way he is. And then I'm actually really blessed. He's super, he's like, a super kid, you know, and I don't have the stemming and the other behaviour, roll tendencies like the other kids do. And I think that made me realise, gosh, I'm actually actually really blessed.

F: Yeah, yeah, I think you go through a process, or at least we did, or at least I think I did. There's a lot of anxiety around the fact that will he ever talk? Will we ever progress? Or will he be like a two-year-old forever, will he you [M: stop hitting], will he stop hitting? Will he stop biting? Will he stop it and all of those kinds of things. And that sort of speaking to what Debs was saying is, I think, in that regard, we've been very fortunate and blessed in that Tate has progressed amazingly.
I remember getting a before we came to Kanyisa. So we've got a speech therapist in and I had written a list of words that he could say it was like about 15 words. And I was trying to get him to say them, and like he would say about three of them. And I'm like he can say more words. And like, it's so horrible, because you're like, you're trying to show that your kid's gonna be okay. Or you can be okay, or he's maybe going to speak? And you just don't know. So that's hard to accept. Yeah, he's like there forever, like, what will that look like? And then as he's progressed, he's just progressed into this awesome character that's like, he speaks, he laughs, he jokes even.
He obviously still misses a lot in conversation and understanding. But compared to then, and what it could be it’s so much better. And I think that's what Debs has been speaking to. We've seen lots of stories, read lots of people, and some autistic kids are, like, really deeply on the spectrum, like, very difficult in very many ways. And we are fortunate not to have that.

M: I think when you're not exposed to it much other than your own kid, you're kind of stuck in the harsh reality of where you are. Yes, your kid. [R: Yeah]. But I think when you're exposed to more people have special needs. You realise how awesome they actually are, and how they have so many other talents, it opens your eyes to what they're able to achieve [R: yeha]. (M: clears throat), so if it gives you hope, I didn't have hope. Until I went to Khanyisa, I had no hope. Because I was like, bummed about it. But yeah, I think and then also driving to school. Normally a boy, young boy at the age of four would go, *oh look, there's a truck* or I'm seeing a forklift or whatever. And he never spoke. He didn't say anything. And so driving to school was always so hard for me because I couldn't talk to him. Even though I could. I wanted to, but or, he would see it, but he wouldn't do anything about it. And even the word I love you was like he just never said I love you. Do you know what I mean now he says I love you love you. [F: now he wants some cuddling]. Brownie points, and I think that it was really hard to to have that sort of silence with him and not being able to relate to him. I think Hannah also found it quite hard, you know? Yeah.

M: The fact that he can express. I'm not feeling so well, or sad. Whatever it is, is and I never had any expectations. So I always guarded my heart, okay. I'm not expecting anything. So even when someone says no, he's, he's gonna live by himself, you know, on his own when he's older. I'm almost like,hmmm, I don't want to think about that. But I want to even like entertain it because I don't want to be disappointed. So the barrier, the defense mechanism is no expectation, but I'm blown away by what

he has achieved so far. But I'm almost silent by his progression because I'm scared. It doesn't get further than that. Just stops suddenly.

R: How do you manage that?

M: I don't know? [F: All the anxiety?]

F: You don't. Honestly, it sounds terrible, but you can't manage it. Spending quiet time, like trying to process trying to just be optimistic. Like doing the best you can for them, for him. And, and just being faithful, I guess like there's like a, saying back then you just don't know. Like you literally just don't know. And I think I realized looking back, that was a great source of anxiety for me, like, like Debs talked about driving the car, he's not talking. Every time I drove him to school, every time I drove him back, I'd be like, talking to him, singing, trying to do something just trying to get a reaction out, right? You could argue with them on purpose, because you get angry with or I'll do something irritated him. So he would fight back and you'd argue back at me and then I'd argue with him and at least got something going. And I actually think it was helpful. But, But yeah, so you can't fully manage it. You cope with it.
That's a good enough answer? [R: yeah of course]. But yeah, you can only I mean, the debs and I both have had issues with anxiety, both issues with exhaust, exhaustion, like really burns out at work, like because of …

M: like im, vigil… vigilant mode all the time.

F: Yeah, you're trying to I mean, we're talking about Tate, but we've got a daughter as well. She's going through her own stuff. She's her own pedantic way and her own things that we've got to deal with. And it's very dangerous to because you can potentially neglect that, because you're so engaged in this and so stressed about this. So all in all, it's not ideal on any family, I don't think but you, you manage it by going um, yeah, I have. Just keep walking through it.

M: So I think was realizing we are anxious, we feel just can't handle the noise anymore, or whatever it is. And you know what she's feeling and she's younger, like Hannahs much younger, so she's had to mature quite a lot. For her. She's quite mature for her age. I don't know if it's because of Tatey or she just is naturally like that. But I think she's had to cope with doing things independently and just the emotional level, on an emotional level. She is quite an emotional child. She's super sensitive. [R: Yeah]. But if we were battling gosh.

F: oh, she she went through that what three years of stuttering she she was. She was early, early achiever, walking, talking, super bright, amazing, like super confident, fearless, everything like that you would kind of hope in a child. One day, I'm not I'm no exaggeration. One day she woke up and she was stuttering. Like from the night before, she was fine. Woke up the next morning she stuttering and stuttering badly, like really badly at times, like up she's giving up saying, [M: you talk to me]. You talk for me. And you're just like, [R: yeah] stop. And that was in the midst of all of our stuff to go, let's go to speech therapy. What are we what's going on with her? Like, I'm trying to deal with that. So. So yeah, I mean, to answer your question again, I guess as you manage, you've just managed like, [M: day by day], go as much as you do as much as you can. Sometimes, I guess at your own peril, because you get exhausted, stressed to get anxiety. But there's nothing else you can do. You just have to do it.

M: I think its also about choices. But I chose not to go to the shop with Tate or do things social with Tate because I knew I couldn't handle it, couldn't handle him. And so obviously, we've got better our choices have changed. And be able to do a lot more so managing it's a lot better. [R: Yeah]. I think I managed anything. I don't know how I ran a business. Honestly.

R: It's crazy to reflect on those days, and you don't realize …

F: and it shows you how far we've come like it is. There is still things. There is still stress. You're banging Tatey. [R: You're fine]. No banging boy. Just now. Yeah. [R: its fine don't stress]. It does bring a tear to the eyes. You think back here. Yes. We were almost dying. Like at that time. It was really hectic. But we're not there anymore. So much. Like he's finally out of nappies way out of nappies, you know, like he's finally sleeping through the night.
Like, can't wake him up in the morning. Like people seem to get there you know, like I don't think so (R: laughs) yeah, so. So yeah, it definitely gets better was when better for us, as I said in the shore, toughness and then now you kind of just deal with things I was like,yeah.

R: Thanks guys. So tell me around the time that you you've got Tate's diagnosis. What, what did support look like to you? And what? What, what was the reaction to your kind of immediate circle? And how, how did you guys cope with that?

F: Can I answer that? [M: yeah, now I feel tearful]. So it's, it's a mixed bag of situations, I guess. And what we found was one, we knew very little about autism, you realise. And so we dove into educating ourselves in all of that, you realise the people around you, just as you were prior to the diagnosis, where they know very little about autism and all that, and you can't expect them to just educate themselves and to know all the answers to everything and how to be. So we found that we had, I want to say a little support, in terms of direct, like things like babysitting, and things like that, like we had our domestic worker who had been with us from his birth, who, who kind of grew with them and knew how to take care of him. We didn't feel comfortable leaving him with any of our parents, or grandparents like, besides the fact that, like, on my mom's side, I think she wouldn't have felt comfortable with that she'll be nervous and worried and stuff. It was just one of those things that she like, I don't think they can handle him, you know, like, we know him well enough. And so there was that. The, we were recommended through the educational psychologist, Lin Campbell, to check out Khanyisa.

So what we found was from that, coming in to Khanyisa, that was like, a ray of hope, because there was such knowledgeable support there. And caring, so and people going, we get you, like we understand what you're going through. Because we were only Debs and I will never understand what we've been through like we know. So to have people who kind of can see into that a little bit and have experience dealing with other parents of other kids on the spectrum or other special needs. They will support there.

M: Can I jump in here? [F: yeah]. So, our family they had no education or knowledge or understanding of autism. So like my parents would, even now to this day, be naughty. And not understanding behaviour. My younger sister, I don't think she'd have any tolerance for kids in general. So she was not very supportive. No one really investigated it other than Stacy later …

F: and my dad as well. Just to note that because my dad went ballistic, like he, when I say we went ballistic like he still sends me stuff, like do this [M: diets] look at this new thing. I think he's really read

more than us probably like on [M: but hands on] that which was cool but also at the same times like I've looked into it I'm not gonna afford to give him this medicine and that medicine and, and this therapy and send him there and just we can't do it all. So but so there was that kind of support, I guess, which is worth mentioning, again, was a mixed bag. Sorry carry on.

M: Yeah, like I think Stace and Nate did some research so that he would know how to handle.. And they were quite open to understanding is why his behaviour he came to they came to IDPs and stuff like that. So they wanted to know more to be supportive, but I think other families really the older generation I guess they didn't really think, they didn't know autism and they didn't get it [R: yeah].

F: just to speak to speak to Stace and Nate as well, they from early on were there [M: amazing]. And and helpful and willing, I think it was us that we're scared to leave him alone with anybody. And we it was really difficult to let go you know, for a good season they would come on a Tuesday and babysit and we got a date night. [M: every Tuesday]. They'll just come and go like you guys need to get out or whatever so, so really a complete mixed bag of support that's from immediate, I wouldn't say community, immediate family and friend and friends and stuff again.

R: Yeah. And from when you got the diagnosis was there a lot of like, this is what your life might look like?

F: It was it was a part a two hour interview to an online interview where she asked us a lot of questions. He was was too young to do a sit down tests and stuff like that and he [M: just wouldn't observed him at school]. Then she went and observed him at school. Then we went back to for the for the diagnosis or whatever the feedback is and she said he's got autism she was amazing.

M: She said sensory processing. So I was like so that's not quite autism. So even I didn't understand that that is now on the spectrum. I thought that was different autism. I just thought it was a sensory thing. Not Autistics. I had no idea.

F: Yeah, but that was the last we chatted to Lin. It was you went to her for the diagnosis. She was diagnosed, she recommended Kanyisa? She was like, this is probably the best place for him. And then off we went in. Phoned Kanyisa and that how our journey went.

R: And then, Jonno, you say something interesting, you said that, when you got when, when you got the diagnosis for Tate that your family at the time was kind of where you were at the very beginning, like not knowing what to do. Not knowing too much about autism, but that you couldn't put that on them to like, know more.

F: Yeah, so it was bad until you. Like my boss once said to me, that, you know, special kids like special needs kids, they're out there. But it's almost like you don't see them, or know them this is when you don't have special needs within your immediate family or friends or situations, like you hear stories. But, but it's like, it's it's removed. Because they go within these certain families and parts and schools and whatever. And it was like it with us were wouldn't have, I guess, thought too much about it or know so much about it. Once you once it becomes a reality for you and your own fate and your own immediate family. Then you're like, wow, okay, now we have to deal with this. And then you figure it out.
But your extended family, your grandparents, etc. Uncles and aunts, you can't expect that of them. I don't think It's amazing. I think, you know, if your grandparents, if the grandparents are healthy, and

fits and whatever, like for sure you can, is there's levels of things that they can do to help. But in general, it's they are where you're at before you get the diagnosis and are forced into that learning curve that like steep learning curve. And unless they have their own autistic kid, they're never going to go through that learning curve that hands on dealing with. So when he's acting up, and we're not smacking him, they're not getting crossed with them. And they're looking at us like discipline your kid, like you're going, you're never gonna get it and I'm okay with that. I'm not going to smack him. Like he's [R: Yeah], that'sokay.

R: All right, that makes sense. Okay. So as you said, John are like, there are a whole lot of special needs kids around Durban. Well around the world, really. But in Durban, we have our community at Kanyisa. But like outside of that, there's not a real presence for children with special needs in Durban, in KZN. They're kind of always that. The last thought like that after, especially like during Covid, when everybody was returning to normal kind of schools that had children with disabilities were the ones that were coming back last. And they were probably the ones that should have been first.

F: Yeah. That's terrible. Yeah, so sense of forgotten, like it not nice to but a word like, but there is an element of that. [R: Yes]. I think not, not front of mind, out of sight, out of mind.

R: So just off the back of that. That's why I'm on this train of community. Inclusion. Belonging. What that means to families. Is the key events, or a moment that you can think of were, where you felt like you belonged within a community where you felt like you were included, or you felt like you could exhale?. You didn't have to try.

M: To be honest, I don't think I'm quite there yet. Even at Kanyisa, maybe this Christmas market, it will be different. I would really like to bring Hannah and Tate. But even functions like that socially, I'm like, no, today, Tate's staying at home it gonna be too much. So I don't feel I don't know if I'm answering it. If I'm understanding your question, but I don't feel quite ready to be involved in a community social event with Tate yet. I'm not quite there. John is better at that. Going out there with him.

F: I think I'm understanding the question slightly differently.

R: Okay, you go first.

F: Okay, well, do you want to carry on? [R: No. No.] So so what I'm thinking is … Tatey no banging please. [M: come here boy]. [R: its not a worry, don't stress. You never have to aploigse]. So to answer your question, the way I understood it is. No, I've never had a moment, outside of the special needs community where I felt everything's cool, can just relax, like no stress, even going to our church, which was an awesome church very inviting, accommodating, you still feel [M: stressed] stressed, you still have to chase them around. If you want to be quiet, you've got to like, you don't feel at all like you're not welcome.

But you don't feel I can just come here and go and everyone will get an understanding. And I can breathe. People don't really like it, you don't fully feel like it not yet. I will say that there's been moments with Stace and Nate, we've gone away and things like that. And it's like it really, really, really tough. It's like, you have to tear yourself away from the responsibility and oversight and all of that. But once you do it, there's a sense of okay, there with probably the best people to be with Hannah and Tate, that we know. And so you can relax a bit, but I don't know if that's looking in the broader community, though, as opposed to it's, it's the aunt and uncle.

M: It's interesting because they don't feel stressed or panicked, or full of anxiety to take him to a restaurant or to take him to church. Whereas we do. They're like know if we kind of handle we'll both bring them back.

F: But we still like hyper vigilant and flight or fight mode.

M: They took him the other day to a restaurant to meet one of her friends. And they love her daughter and Tate had a coke and had a great time. I'm not he ain't going to no restaurant. Couldn't do that.

R: That's funny that they are okay with that.

M: For some reason. Yeah, we're not quite.

F: It's because it's small chunks for them. It's not a permanent. They come once in a week or two weeks or whatever or an occasion and do that, and then it's over. It's easy to manage anybody I think it's so don't beat yourself up sort of thing. When you live it all day, every day. And you are hyper vigilant, you are having anxiety and you go I'll choose the battles I can fight and at the moment im not ready to fight that battle.

R: Totally if I think like I think about it for me, like the number of times parents are like oh, you guys are amazing for what you do. But actually, we like this is what our whole day is dedicated to. It's like four or five hours of the day. And then those kids go home to parents that now need to continue on with what is happening. So I would say like, as someone who isn't immersed in this environment all the time, I have more capacity, because it's not my everyday.

F: You're able to just connect and discharge and whatever. Yeah. Well, that's why school is great. You can drop them off and charge for yourself to go straight to work (R: laughs). See ya later.

M: That's why parents moan that's theres no holiday club or stuff like that. Because they, they need the support.

R: Absolutely. So Debs to come back to you. So I was looking kind of like, if there is like a moment that stands out to you. We were like, okay, cool. Like I'm with Tate, and it's fine. And it's like, I don't feel like I'm judged here. I don't feel like at the end of this experience. I'm an absolute wreck because people have been looking at my certain this certain way. If there's any event or moment in your life, that you can remember where you didn't feel judged when you felt like it's okay, that we're here.

M: You think go like on a personal level, like a friend, like go to Tam's house or Jessie and Noah. It's so easy. It's absolutely fine. I think it's when it's going out to people that don't know. That's difficult.

F: Also, you don't feel judged. You feel like you want to prevent judgement. So you can't say like, shh, stop. Okay, I've been been to helicopter parent a bit because you want to keep it at bay. You don't want it to escalate.

M: Even dropping Hannah off school Tate like, gives like a scream in the car. And Hannah freaks out. And she says before she's even done anything. She's like, Tatey, please don't scream at my school. It makes me very sad. So even that I'm just dropping her off at school and she's embarrassed by him. So

in those years, if it's a personal thing, it's fine, I guess with certain people. Not all friends. It's very limited. But yeah. I don't know if I can do public occasions. There are occasions, like I took him to. I can take him to Checkers, and it's been fine. But I'm still on edge. [R: Yeah], I'm still like, okay, can't be here for long only, like 10 items maximum. Yeah, you know, I've got to make him realise he can't get a sweet or whatever. But I do it, but it's much better. I never used to be able to do.

R: Yeah. Okay. And now it's also a good time to chat about Hannah. Does she know about the diagnosis about what that means what that looks like?

F: Yeah, she does. She gets it that he's not typical. She understands, I think, to some degree what autism is. Just because we've explained it to her and all that. It was a period when she was a bit younger, where I think she was starting to understand what sicknesses and things like that and she was nervous that she could catch autism and to kind ofexplain to her, like no don't worry, you can take a quick kiss, I'm never gonna get autism. It's okay. Like, I like to really show her that you know you don't have to worry. But yeah, I'd say she's got a an age appropriate understanding of what autism is. She's not gonna give you the dictionary definition but she she understands that he's his brain doesn't work the same. His development is slower or different. His reactions to things are different because he's sensory is a sensory seeker [R: yeah].

M: I think she's got some empathy, like, we made I made a video of Tate ages ago, or what was it? When you went on the helicopter, I cant remember, it was a video with some emotional music, and even Tate, he cant watch it, he gets quite emotional himself, but Hannah like feels bad for him. But on a social, social level with your friend, she's kind of embarrassed because I think she can't explain it. So she feels sorry for him and sad about it. But she's also frustrated that they actually fight like typical kids sometimes. And that's quite amazing for me, because she gets to experience that. And bit of normality. But I think there's, there's moments where she wants to teach him actually, she really wants to learn.

F: Moments where they play amazingly. Like she'll take him all around the house. Yeah, like, it's really. It's a spectrum. Its up and down. [M: Tatey come]. But for the most part, she's very, she's very well understanding for her age. For a nine year old.

M: When we go to Kanyisa she doesn't want to be around the kids. I think it's because she doesn't know what to do. [R: Okay]. So she feels a bit overwhelmed by them. Or shy or not quite sure. So I think she's still, but she wants to help them. She wants to do horse therapy. Yeah.

R: Okay. And how do you how do you nurture that sibling relationship?

M: Oh, gosh. I don't know if we nurturing right now (R & F: laughs). But uhm..

R: Or how do you think they experienced this relationship?

F: So I do my best to, she will get super upset when he does something that irritates her, or he'll touch her hair. And she'll freak out. He gets upset when she does something. And so they do find like typical brother and sister, but with slight differences that he doesn't fully understand. And sometimes he's just testing something because he doesn't quite know what the response will be. But she's taking it personally. So I'd do my best to try and be like honest and dissect it and defend them in their own right as to what's what's okay and what's not. And if that makes sense? But if she's right, I'll let her

know she's right. If he's right, I'll let him know. And I can only be as honest as I can in that and then figure out the rest and try and not let them fight and stuff like that. We just encourage them to play together and not spend too much time on the phones even though they do.

M: Yeah, I think when she was younger, even now it happens sometimes but uhm, uhm, the situation would come where it's quite intense at home. He's screaming the dogs barking. Hannah freaking out, or Hannah would freak out. They scream that high pitched scream and I'd be like, oh my gosh, and she'd be like Tate da da dah. But his autistic. I'm like that she actually really get that you would get that but it's the only way I can. He does not like our brain. So there's a frustration level to try and get him to understand shame. So I think she's had to learn quite quickly (Tate making noise in background) about what that means wanting (Tate making noise in the background)(Everyone laughing).

F: you are entertaining [R: I love it!].

M:but an interesting thing was we had neighbours, and they were amazing. It was another Hannah and and Megan, and Hannah had diabetes. And Megan wanted to be a therapist an OT. And so Hannah. [F: Six? Six or seven?] Yeah.
So Hannah, and who them used to play all the time. And Hannah saw how Meghan, the one who wanted to be a therapist, who has gone to therapy herself, and that's why she knows she wants to be a therapist. She gave such grace. She let him because Tate also stuttered. And so she would wait for Tate to stop stuttering. And, like be so gracious and beautiful with him. And because Megan had, not had a disability, but she had diabetes, I mean, Hannah, the other Hannah, had diabetes, or she could never come to play at a house, they had to stay at the fence, because she couldn't be far from her mom because of the readings and everything. So Hannah understood that she was a friend that also has a condition that now needs her to be homeschooled.

And I think that really helped her because she felt accepted. But she wasn't the only one dealing with something that's different. Now Hannah and Megan were there, and Hannah, other Hannah, was dealing with something that was different. And she could see her Megan was so calm with Tatey, it's really was an amazing thing. And I think Hannah almost not accepted it more. But she realized it's not so that she realized that she's the only one that has a sibling that has something. So talking about community, I mean, that's amazing for her to realise through other people, that she's not the only one who has a brother, or sibling that's got an issue. Yeah. I missed them.

R: And then Debs you mentioned earlier, John, are you creating some audio books, for Hannah for bedtime? Can you tell me a bit more about that?

F: I didn't in a sense create them for Hannah. So I [M: for us, for all of our kids] realized that. So Hannah was starting to stutter, I forget the exact perfect timrlinr of it all. But I just knew intrinsically, and you could kind of see it that she was taking a bit of strain. [M: And especially a bit of time] at bedtime, our attention was sometimes Debs would be exhausted and Tates screaming, trying to get to sleep, whatever. So I'm like, okay, don't worry, let me come and help. Deb's would like take a moment, or vice versa? And Hannah's there also needing attention. And there is this real screaming in the background and real difficult situation and exhausted parents. And I could just my sense was that it was taking a toll on her. And she needed to know that her parents were okay. She needed to know that things. Were cool. So I just started spending time telling her stories. So I had not I will just sit down with her and yes, sometimes just so broken tired, how do I tell a story like and also I looked online, and I couldn't find much that was just freely available or quickly available. Other than other

books that people have written, maybe really done out as an audio. [M: They weren't nice], they were long as well, like, a story. So I would just start telling stories. And then after a while, like after one or two, I thought these stories actually okay, and she's enjoying them. So I just started recording them on my phone. And after a while, I built up a few, quite a few stories. And, and I realised there's certain days where Tates really stressing and Debss trying to put Tate to sleep. And she's taking strain. So I was like, Hannah I need to go help. I'll come back just now and I was like I've got a story on my phone, I can just play it for her. So do you want to listen to the stories. Do you wanna listen to the stories? Yeah, yeah, yeah, the one that bought the bear or whatever.
So I'll just play that story for her and help Debs or go and sit down in the lounge and just take a breather, because as I say we were like hyper vigilant, always on stressing, and we were taking strain as well. And, and I did that for a year and a half or something I forget. And after a while, I had a whole bunch of stories on my phone and it became a thing to go Hannah I'm too tired to tell you a story tonight. But which one would you like to listen to? And she was quite okay with that. And so she would sit and listen, sometimes two or three.

M: So she would like add to the story, which is kind of sweet.

F: Yeah. So I mean, I had them on my phone and it was a while later a year plus two years later, whatever our something and maybe I could write them as children's books or turn them into stories, whatever. And I couldn't quite process that as a lot of cost involved. Printing all those books and you got to do numbers and stuff like that. So I realized I thought was off the something here in giving parents a rest when they're tired because every parent gets it. And there's something helpful giving a bedtime story to a kid. That's not just a quick read of a book or whatever. It's like actually in an immersive story that you can really like hear the sound effects and stuff. So I turned those stories into that sound effects and voiceovers. Yeah, and then, and then she still sometimes's listen to them and Tate as well.

R: that's amazing. It's really amazing.

F: So that's, that was kind of it never started as I have a plan here. Not at all. I don't want to read a book. Again. [M: I don't have the energy to]. Can't find anything quickly on the internet. And I'm just going to tell you a story. And really sometimes it was bottom of the barrel like digging, like just start he was a mouse. He's leaving his house. Okay, Mr. brother's name was just writing and okay, and next thing you know, 20 minutes later, you've told the story and it's like, and it's kind of this little voice in the background like, I'm not gonna do this tomorrow, I'm gonna wear makeup. Like tell me about your makeup. okay. Can I finish the story? (R: laughs).

M: if you go back to the to the recordings. That used to be making a video that you get it's them screaming, and you got you and all honesty. It was hectic.

F: If I'm not embarrassed, but it's, it's private in the sense to sometimes those moments because he had Debs and are arguing, you hear me sayind Debs just do it like this, whatever. Okay, I'm sorry Hannah, im coming back again. I'll be back. And yeah, there's real raw moments of distress. And it's like, I actually haven't gone back and listen to the ages I'd like to because it's those beautiful moments were endless. Like, it's not a mine. It's a porcupine, porcupine tomorrow and she would completely get engaged and talk about the story, but then also, tomorrow can the porcupine wear lipstick, like okay whats that got to do with the story? But she would completely get engaged and talk about the

story. Sometimes make up her own. So there's those beautiful moments. But there's the grueling moments of okay, she wants another story.
How am I going to do this? And then there's those tough moments of like, chaos where and that's where she was in that didn't realise that's why she needed appearance to be able to sit down and go.

M: Also the stories he did was about bravery, friendship, courage, endurance, like all these qualities we want her to know and you know, so the stories are about that about helping friends, about the we different about all those kind of things. I think it was also indirectly you actually try to teach her stuff.

F: That was a thing. Yeah, but everything's gonna be okay. And it was always a positive ending and a difficult situation and a solution and whatever, like, everything's gonna be okay.

R: And then, bit of a difficult question.

M: I'm already crying.

R: Sorry, Debs. Do you remember? Is there a moment or an experience that you've had where you have felt marginalised or excluded as a family because of Tate?

M: Ah I don't know if this even even now, I'm feeling that way. But I'm arranging his party. And I know having a kid with special needs go into party is very difficult. Now when a party for my child inviting special needs people, and they almost don't want to come. So it's not because of Tate excluding Tate. It's excluding the fact that their special needs it's because they special needs. That makes it difficult. So he gets excluded off having a party. Am I making any sense?

R: yeah they are. Almost those families are going through the same thing [M: exactly] of that stress and anxiety having a party or going to a party. But that means it Tate can't have a party because those are his friends. [M: Yes].

F: Yeah, I interact a lot with typical, typical boys like we've got one or two mates and stuff. I get my mate to bring his kid along and stuff again but so it's a bit like every year we feel bad about his party because it's always a little bit like smaller, less and less people involved. Also we're exhausted after Hannahs party. We try to do something nice, but it's like, the crowd is small. The friendships are small that can say you feel a bit bad.

M: socially, were not really invited too much. But it's because in the past we've said we can't go so I don't know if it's because they know we just won't come or because they just can't deal with don't know how to handle Tate.

F: But to say from a, I've never felt marginalised. I've never felt. I think marginalised… is not the right word, like I have never felt anyone like to kind of shun my presence [R: okay] or whatever. I felt the personal pressure of not letting Tate's have a tantrum or act up or scream in the shopping centre, we took them to the movies up to crimson news the other day, and he managed to sit through the whole movie, but the whole time I was stressed that he's going to start talking and say, and be loud, and then people are gonna go shh shh. So when he does start talking im like Tate, we're in the movies, and he's

like, what do you mean? It just triggers a conversation. Just so it's there's that anxiety but you don't feel marginalised you feel you don't fit in as easily, you don't have a licence to just be yourself, because it's going to disrupt other people's peace, and lives and all that. And that makes you feel like, you have to be a lot more careful. And on top of things and I guess controlling, or what I don't know what the right words are. But you have to be vigilant around that. And even though in many situations, you would maybe act up and stuff and people wouldn't care. But you still like you don't want to disrupt.

M: Also, what we are experiencing is, for example, I think we exclude ourselves, because we are. A, he's like, for example, Hannah's Spur evenings for school. Every kid wants to go to Spur evenings with the school and we just won't even mentioned that, because A gluten he can't eat there. B he's gonna go crazy and Hannahs gonna be embarrassed, almost like, exclude ourselves, because I don't know what it's gonna be like.

F: Yeah, so we split up, especially the beginning, it was a big period, two or three years where they're like, Okay, like, you stayed home today with Hannah, I'll take Tate to the beach, like, Okay, you stayed home with Tate, I'll take Hannah to Gateway, or vice versa. So there was there was a good period of time that we split up in order to manage, because you can't do we tried to go to the gateway, and he turns around wants to run that way through all the polling, and you just go, you go home fighting and stressed and it just does not do that again. Like its not worth it. So as I say, it's much better now. And I do push myself a bit to go, like, took them a little game drive the other day and stuff. But it's still I know, it takes a toll on my anxiety. But like, I feel too bad that they miss out on things. So you can make it happen. Like you have to kind of force it. But I've never felt shunned or marginalised. Like, it's more indifferent, like you just part of society and society is like, carries carrying on without you in a sense, they're just carrying on with life, and you dealing with your your world, and they don't really know or get it until you're in that space. And then they have something to say or do it but then you're out of this space at the end of the day, and life goes on. So exchanges are just fine.

M: I took Tate to spar the one day. There was the most horrific experience in my life. And she looked at me with disgust [R: what happened].

F: Like, I would have said something to her. Lucky I wasn't there.

M: I was so traumatized. I was just speechless. It was just the most it was it was the most horrible experience ever. And all I wanted to say to her is you don't understand. He's autistic. And and he was screaming at the till and and I think also culture wise people didn't understand. So it was just the most horrific thing. And he was still screaming and they looked at me like he is just a naughty brat. Like give him a smack, why aren't you disciplining him? How are you raising this child like all these things? You could see in their eyes that that's what they're feeling. And I was so traumatised by it but looking back or would have gone. Excuse me! Can you not look at me like this? Do you understand what you know and try to but it's just wasn't in our place. I got in the car I literally got in the car and I sobbed my eyes out. It's just terrible.

F: This is my personal to me. I don't know if I can speak for you. But the scary thing is that before you go through autism, personally yourself in a situation if it just wasn't in your world, and you walk in through the Pick 'n Pay or the Spar or whatever, and there's some lady there with a kid who's just freaking out, throwing a tantrum on the floor. I wouldn't do what she did. Not give you death stares

but you will have the thought like yus sort your kid out. So you can't, when someone is, like as blatant as what you're describing this hectic like they, I would have said something to them. You can't do that. But that's what I said earlier, you can't expect too much from people *because they just don't know*. Because they're just not it's not in their world. It's not their paradigm. They haven't been educated for it. They just have no clue. So, they just think that's a naughty kid and that mom doesn't care look.

M: My parents. But also, it's not that Tate has behavioural patterns that show he's different. He does. But he is like, he doesn't stem. He doesn't. We don't have to do MaKaton for him. So if I started doing that, in the shop, people might go, oh, he's a bit different. But he's doesn't look, if you're looking at me, he doesn't really look like he's autistic. And until we really know him, so he would instantly look like he's a naughty boy. Whereas if our if he was in a wheelchair, or he wasn't talking, and I was signing to him or something else, or showing him visuals or something, they might go. Okay, and have a bit of grace. But yeah, I think because he just looks like a naughty brat. Going through that meltdown.

R: You read my mind with my next question. That was to say that in some countries, autism is classified as a hidden disability. An invisible physical disability. [M: So sad]. Because it's not something that you can physically see someone with Down syndrome or cerebral palsy. It's more, it's more…

F: What is the purpose of the diagnosis? Is that so many I've heard stories about cops arresting kids, or teenagers because they are doing some crazy behaviour or whatever. This is, like moving the States or elsewhere, only to find out later that they literally cuffed an autistic and like, everyone's freaking out. Is that why it's, it's classified as a hidden disability? So that people I don't know?

R: I think that part of it is to raise awareness. And then I know like, in countries where it is classified as hidden disability is like the UK. And the Northends have said like they have specific campaigns for invisible disabilities. So someone with epilepsy, with autism, even with high anxiety, schizophrenia, bipolar disorder, all of those are not something that you can see. But they need awareness in the community. So you know, when someone is acting in a certain way, it's not. It's not that they're crazy, or they're trying to cause trouble, or something like that. So they have like a sunflower campaign where you get a lanyard. And then everybody knows what that means whenever they go somewhere, that is to signal to other people like she's got a hidden disability and staff are trained and everyone knows what to do when they see it and the person needs help.

M: Like I know when I spoke to Sxxxxx about them travelling, she was at Joburg airport, and Mxxxx, had a complete meltdown. And everyone looks at her like with just total judgement and all of that. They got to the UK and they were in the passport control. And they were in a queue. And this lady came to them and said, are you guys okay? Can I help you? And she said, no, my daughter's autistic, she's had a rough flight, it's been a long journey, she's just frustrated. And she was like huh and she took them to the front and let them through passport control without waiting in the line. [R: awareness]. You should even have to wear anything to say I'm autistic and often before I used to think I need a t-shirt for Tate and then I thought no, but that's really mean. You know, but how else do you tell them? And I would have …

F: Yeah, I was gonna have since found out I saw a video on YouTube that you can phone ahead to the airport and say that you have a special needs child. And not only will they like put you to the front they will let the entire trip know that you get special seats like that I've literally catered to you in I don't know if it's all airlines, [M: but I don't know about South Africa though?], South Africa.

M: Stuff like that. Because it was gluten thing. I've heard or seen that there's a lanyard you get that gives a message that says in all different languages [R: hmm]. I am gluten intolerant, I can't have this this this. So if you go to a restaurant, you're travelling, it's called like a travel buddy or you're travelling whatever language it shows up in whatever language and I can't have this, this and this. And it's like they do that for gluten, but they don't do that for autism, or anxiety or whatever. So now?

R: Which makes my next question for you guys. Have what do you think makes an environment or community inclusive?

F: A lot of things. [M: yeah]. It's so it's so hard to answer that question in a country, like our country, or to speak negatively about our country. But but there's no education, if the general (so perfect world scenario) if the general public are educated to special needs, and what it is and how to identify and how to react and how to respond. When you see a special needs child, that's a massive step towards inclusivity. How that programme works, what unfolds or if it's done with in high school or whatever. Who knows. But that's, that's a big deal. Because I think, like I said before, like, like, Debs and I are in the same boat, you're just not aware.
Like before you watch a movie, and you think, wow, autistic kids are geniuses, or wow, like, that kid can do math, like, crazy or whatever. But, but that's as far as you know, really, unless you have first hand experience. And so the education level is, and especially in our country, if you if you think about the majority community, like you've said before, they come from a sort of traditional, ancestral, religious sort of background and understanding. So they often think that special needs are cursed children or witchcraft or things like that. And you can only imagine within their communities like how that plays out. Like, that's not just exclusivity, that's like being shunned being excommunicated, and things like that. And so, step one, is about communication, like to communicate the necessary communications. Sorry, I said communication, I meant education, to educate people. Let me think about it a little bit more. Because that's a that's a big one. For me. It's, it's encompasses a lot. [R: Yeah, absolutely]. Debs do want to say anything?

M: I think what I realized, as John was talking is that when people first see, for example, Tate being autistic, there initial realization is what we realized when we got the diagnosis. It's almost like, it's not so emotional, but it's like a shock of what is this mean? And, and people don't know that. So I get the fact that they find it hard to understand. So yeah, awareness is huge. And communicating, we need to talk about it, we need to be able to hear on the radio, like, you must be articles about it, like, put it out there. So people know, like, have a Down Syndrome person, as a model, have an autistic kid as a model? Those kinds of things like just communicating with the world with them. I think will …

F: I think what you alluded to just now as well. I've heard of small things, I guess, but not quite to the level of what you're talking about. Programmes where like kids can wear a lanyard or like different kinds of stickers sticker on the car, or whatever, they're when there's different ways of, because you can't expect people to just know as well. So different ways of communicating that from the special needs community out. That's understood by the rest of the community. That's that's like, like a stop sign. Everyone knows what it means. Like a stop sign. Everybody knows. Green robot, everybody knows.

R: So something more universal as a sign? [F: yeah, I think so] so that people immediately know.

F: Yeah, so if a policeman if a kid is having a massive meltdown, 18 year old kid, being autistic kid is freaking out and having a meltdown. Cops don't show up and pull a gun, or try and cover or try that sort of thing. I don't doesn't happen too much. I don't think in our country, but I have a lot of stories. And that's, there shouldn't be a way of knowing straightaway and protocol. So how to deal with that. Thank you with a little bit of time, I could think of a lot of things.

M: Think also like I wish schools taught sign language, because you meet somebody on the bus at work, or a sibling of somebody or somebody and they can't communicate how amazing if you can just pull out some sign language and they feel so included.
Not that it has to, just making that more way like those guys came to Kanyisa and I wish they would go to more schools. So that even the gesture of Hello, can I help you? is known worldwide, almost like it's part of the curriculum, you just got to know certain phrases any time. Like that would be so amazing!

F: So like, I know this is available in our country to some degree, but integration into mainstream schools and support to help kids get along that way. That's, I guess more governmental run stuff again, because obviously, there's private entities like Kanyisa or whatever, that are expensive. And, you know, like, No, it's not available to everyone. So to have a countrywide mindset of there's ways for people to integrate into society or into a have a, what do you call it? Like? A hands on carer in the classroom, helping a kid in a special needs situation? [M: facilitate] facilitate, yeah that's the word. Things like that. And another one? Yeah, this is a few things.

R: There's so many. There's so many things.

F: I had another one, but it's not coming to mind now. Yeah, wasn't it? I mean, there's lots of little things, and lots of little intricacies and stuff, I guess. But the main one, I think, is education. But people that I think it should be proud of high school curriculum, like to go like you spend a term or a year or whatever. Doing that as a subject, you know, obviously, you have to write your high school, but just to make people aware. Because it is very much a undermined community. If you're not in the, in the special needs community, you don't even really know it exists. Just carry on in your circles and you laugh and you go out and work and you do your thing. And until one day you fall pregnant, and you find out yep, just to get a new life. Okay.

R: So, yeah. And then I have a left field question for you. Is there any way that we think Tate and his diagnosis positively impacted your lives? [M: Just can you say that again?] Sorry. Is there a way? Have you found that there is a way that Tate and his diagnosis and positively impacted your life? Because obviously, it's, it's been really hard.

M: wow, that's a tough one.

F: I'll answer I can answer that question. Because you hear stories of people going through trials of many different kinds, some way worse than autism, some not as bad, or whatever. And most of the time, they'll say something along the lines of it's helped me see things I never would have seen before, helped me understand myself in a way I never would have understood before helped me grow in a way I never would have grown before. And that sort of thing. So I can say that, for sure, like autism has, has forced me into places that I never would have into personal inner places that I never would have gotten before and having to figure things out and deal with things in process. So that's positive. Besides that, you get parents who are like, autism is not a condition and like, my kid is perfect just the

way they are. And I just can't subscribe to that. Like if I could pray and he's healed or click my fingers. And there was no autism. I would take that in a heartbeat. But so yeah, it's a really, really tough one to answer.

But I'd honestly say like, yes, at the moment, as I think about it, that there's not a lot of going like, it's changed my life on the positive in this way or that way, other than what I've had to learn and dig deep and grit and all of that, like that's, and that and that's, that's a big deal. That is a big deal. That is it as any trial would be. You don't build that character with that, or that experience or that understanding without a trial. So I don't know if that's a reasonable answer [R: absolutely].

M: I think on a personal level, I've never knew I had the courage or the patience. (Tate in the background, excuse me, can you check your messages?). I have that I do have, yeah. And then on a professional level, it's got me to work amongst other kids and other beautiful people, which I would never have known before. And it's it's yeah, it's taught me a lot. I can't think of all the words, but growth is one thing and he's forced me to grow. He's impacted the way I can feel massively separate. Like a different love. That's the wrong thing. It's like a different emotion. Because he's not helpless. But I don't know what his future brings. So my capacity of emotion is a lot bigger. Yeah, difficult one. Yeah, hard.

R: Last question. And I know you said that it's difficult for you to dream and look far ahead in the future. But if you could think of what community would look like for Tate, or what his life would look like, in 10 years time. What do you see?

F: Before we answer that question, I remember what my thing was (M & R: laughs).

R: okay tell me. Tell me.

F: I came back to me. Debs, you we're telling me about in Australia, they've got programmes where the kids get jobs. Like they deliver the post or whatever, it depends on the abilities and capabilities. And I don't think there's anything like that in my country. So so that kind of stuff is to create inclusivity through work opportunities, job opportunities, work in a coffee shop, becoming a jet engine engineer, as Tate might. Whatever, like that's, so that was, [R: okay]. No, that's sorry to interject that.
R: but no, that's perfect. It kind of lines up with that question. Yeah, 10, 20 years time. Yeah, that would be amazing for Tate to have somewhere to go.

F: Hundred percent, that's our biggest fear. That's my biggest fear. Is was what will life look like for him when we are not here? Or when we are 80 and he is 40. Like what is that going to be? It's a scary thing. Sorry.

M: You I think I was wanting to be stoked. I just want him to be content with what he's doing. Like, I can say I'm guarding myself having expectations. But my dream for him is to feel like he's achieving within himself. So whatever that may look that whether he has a girlfriend or not, like I always when he was younger, I was like, no, he's gonna play rugby. And I've had to just throw that idea out. There's not going to be that sporty sportsman. But maybe he will be? [F: no his gonna be a surfer and a wingsuit]. No I'm so scared.

F: I asked him, I was like, What are you going to? How will you get to the ground? It is like, I'll pull my parachute. I'm like, what if you're watching on YouTube?

M: Yeah, I just want him to be feeling like he has a purpose. Yeah, he's getting up in the morning with he's living with us whether he's living on his own. He's got a purpose. He's going somewhere that he's able to. It's also where the country thing is hard for me because I want him to be able to get on a bus and go somewhere and meet his friends. Whatever that may look like, go to beach. And I think it's hard to have that expectation. Yeah. Because it's not happening at the moment. So yeah.

R: All right. Well, I am out of questions [M: amazing]. But I just want to say thank you so much for sharing. I think this is. This is my fourth interview. And I think yours has probably been the most raw and real. And I really appreciate it. [M: Really?] Yeah. I think I think that maybe the personalities that I have interviewed have been the search really hard for the silver lining, kind of families. And I think also as another layer to that their disabilities were more seen. And so it was just very interesting to hear your perspectives. And just like, like the real honest struggle of what this was like, it wasn't just, you know, like, a delayed milestone here or there. It was something that like, impacted every one of you as a family. So I just wanted to say thank you for being so vulnerable and for sharing so well for giving us I couldn't think of anyone else. And I would rather Oh let's go and let's start Kanyisa New Zealand. [M: Yes!] And then it'll be fine!

M: I've got my five year plan. We're going to be in Australia.

R: Yeah. I would love to hop across and then Sxxx and I are gonna start Khanyisa in Australia and then we'll need Deb's who will be overseeing time for retirement. [M: Australia].

M: Thanks for …

R: Yeah, thanks guys. Sorry, I had to ask like all the hard questions.

M: it's hard going back in time.

F: You're lucky you grumbling and moaning To be honest, I'm just struggling. Because it's like, what? How you guys what's going on? Tell me about autism? Okay, well teach. It's pretty tough. Like it was, like four years later, and then it was like, it's like, just sad. Like, but it's it really is what it was. Like, if you can't beat around the bush like, yeah, it's freaking hard.

R: hundred percent. That was your reality. Yeah, it's important. And I feel like those are the things like that these are not questions I would ask you in a case history. If you came to me as a speech therapist. These are not things that I would consider. I would say, like, thank you for coming to my session. Here's homework.

M: Even to this day, I like battle with Tate’s homework?

R: Yeah. Yeah, no good. I mean, this, this, this is what people need to hear. Because, like, why am I working with you on alternative communication, when like, the whole of Spar could be educated and I have capacity to do that. It's like I education and training as part of my scope. Why? Why am I not being? Why is it always on you? Why is it always on Tate? It shouldn't have to be that way.

M: It's something I've thought about, just add on to one of the questions. Right, so [F: wait…] no wait im on my train of through don't let me lose it! [F: okay go]. Tates diagnosis. And what's happened, has allowed me, which is really amazing now that I think about it to be there. For other parents, too. I can think about Sam and Sarah in the parking lot of Kanyisa. So we often had left the class literally dragging our heels and we find each other crying in the parking lot. And to be able to have, and be that encouragement to somebody else takes takes autism is allowed to be there, which is really, really nice. And I often found that families just retract, and they, they're too scared to talk about it, because it's quite harmful, but or hurtful. And I think they're going to get more hurt by talking about it. But actually, it's created a platform for people to connect, and to help and to encourage it's amazing friendships when you're feeling so lost.

F: I just want to understand something. So you're doing your doctorate on how to uplift or well educate. What's the word? Uplift the community into greater acceptance, understanding? And then you go to New Zealand? (R & M: laughs).

R: Yeah

F Hold on a second.

R: But that is what it is 100% . So New Zealand has like, policies in place, they have things in place that will help me understand. Like, I would love to, I would love to go there. Like, what makes it sustainable? What makes it actionable? Like we have white paper six and white paper six has been white paper six for like the last 20 years, and nothing about it has actually been done. They have so much in the way of what inclusive education should look like. The role that I'm going to specifically is within the education system. I'm just like, I'm dying to pick their brains about like, how, how did you make it happen? And my work is still very much here. But I just think I'm gonna have context for what I'm trying to do. Am I took a tiny bit of a roadmap, but I hear you what needs to be done.

F: Hold on a second here, it's just dawning on me.

R: If Covid, if Covid has taught us anything. It is that you can make a difference from anywhere. Is that what we're saying? But that was also very good question. Like I would honestly just love to know and then learn how like how it can be done.

M: Yeah, I think it's the best thing you can do.

Transcription of Community Interview (Tate)

Codes	R= Researcher	A = Aunt (interviewee 1)	U = Uncle (interviewee 2)
	(text)= description	[text] = adds a word in	*Text*= emphasis

Background

S and L are Aunt and Uncle to Tate. They were identified by the DaCanhas as people who make them feel included when they are out in the community. I had met L once as he attended an IEDP (Individual Education Development Plan) for Tate when he first started at school. I had not met S before the interview.

S was contacted telephonically and via WhatsApp to participate in the study. Once initial consent was obtained, the interview was then scheduled via WhatsApp. The interview took place in person at their home in Durban North. As the interview took place in December, both S and L had flexible schedules that allowed them the time to participate in the interview without the stress of a busy day. They were given a bit more background to the study and the researcher clearly explained the purpose of the relationship. The interview took place as follows:

R: Amazing! Can you just both say hello so I can [U: hello][A: hello]. Fantastic! Cool just gonna put this here alrighty so basically my project is listening to stories of families who have children with special needs and then looking at their community relationships and finding out what makes an environment particularly inclusive or exclusive. How it all came about was there's a little girl that used to come to Khanyisa, her name was Mxxx I don't know if you her? You probably knew her mom Sxxx, if you did know Mxxx. But um Mxxx has autism and um she was like your typical, she loved to collect things, that she like she wanted what she wanted, and she couldn't get her away big tears meltdowns and that kind of thing. And so Mxxx was one half of a twin and so she … Hi! (talking to the dog).. she um.. they eventually immigrated to the UK and so I kept in touch with them and so Sxxx was telling me about how different things are for them in the UK even from the time that they arrived at the airport in South Africa to the time they arrived at the airport in the UK. Mxxxx, she like, she wears ear defenders cause she gets quite overwhelmed by loud noises and at security in South Africa she had to take them off to go through security and they had a spare in the bag that kept telling security promised that nothing in it. Like you send these ones through the scanner and they were just like she has to take it off its gonna beep. So that was the first big meltdown after which they still had to wait to the passport control line and you know how that snakes [A: yes, yes] um so they just did basically said it was like disaster from start to finish, but when they got to the UK they told the airhostess on the plane, this is Mxxx she's got autism. She was like no worried they like made accommodations on the flight which was amazing for them but when they got to the airport in the UK she was like just can you wait for five minutes and I'm gonna get someone to help you.

They went on this fast track behind the scenes way into this private room where they could wait with Mxxx till someone came to them did all their passport stuff and then they were free to go [A: what a difference]. So basically I was like that's not OK like for that to happen to them here and then to get to the country and have that happen to them um and she just said like it's chalk and cheese the way that they're able to take Mila out now because they have this thing called like a sunflower lanyard that she puts on that indicates that she's got an invisible disability. So obviously you can't see autism people

perhaps you know schizophrenia, bipolar, epilepsy, [A: so you're aware?], yes you're away and she said everywhere they go people are trained on what that means. So if he is having a meltdown supermarket like someone is there and they're either helping or they're ushering people along so that they're not staring yeah and I was like why can't we have that? So like it's such a small thing so then it made me start thinking about how as SLT when I'm working with the kids, I'm working with the kids and their families but that means that the burden is always on them. To change. To be different. To be… for them to change the fit in. Whereas things like that exist in other places where they don't have to try so hard. This is my goal, I want to see how we can be more active in communities um and so I have done interviews of four families so far and then from there I've done their community interviews. So in the interview they would have highlighted people that make them feel included or places that make them feel included, so it's everywhere from a lady that was a coffee shop, to you guys, to security guards at a complex and that have very very place where people feel included. So I just have a few questions to ask you guys about inclusivity, your experience with special needs, Tate. Yeah.

A: I think we might love him more than his parents (R: laughs). I think he loves us more than his parents!

R: That's beautiful! So tell me, tell be a bit more about your relationship with the DaCanha's. How do you know them? And how do you know Tate?

A: Debs is my sister, Jonno was one of my best friends years ago, before he even met Debs, and so that she came over and that's how they met. Uh yeah L also knew Jonno from like years before, just school and whatever.

U: Yeah I met Jonno at Harvest church, not from school, [A: oh]. And obviously I met Debbie through Stace. And then Tate obviously being our nephew (R: laughs).

R: OK and tell me what was the process of Tate getting his diagnosis? What was that like for you guys? I've just heard from Debbies and Jonno…

A: We go to Emmanuael church and there's a boy who goes to your school uh um, Rxxx? His mom? [R: oh Axxxx!]. No Jxxxx, [R: Jxxxx?], Jxxxx Jxxxx came to our church and I watched as he was involved with the kids church at the time but I used to see how he acted towards things and he's very sharp. He knew all the characters of the Bible; he knew who was who. You can see that's special, um and so I just started seeing similarities with Tate and so I just to Debs maybe just go check it out? Cause you know he'd look linear at a table with one eye, shapes and angles, and like something's not right here and just go and check it out and I did check Tate out and then I figured it out.

So it's quite amazing because we kind of prepared beforehand um it's not that they thought there would be anything wrong but it actually just helped it cause they we're alone like guys I got to tell you this is the problem [R: yeah]. We were sort of there for them this whole process through. But then obviously watching them deal with this changed over the years [R: drastically] when he wouldn't talk or he wouldn't this and he's still changing um so that was, we slowly figured it out with them and we learned a lot from them because they got really worked out quite quickly with the whole thing.

U: I think it was about about two and a half? Three? when he was diagnosed. I mean I didn't really notice, I mean he was just different, he was quieter, he was different and I just thought he's just a different kid so I didn't really think too much. And when he was diagnosed it was a bit of a shock as

you always hear about autism [R: yeah], but when you are faced with it, you realize you know absolutely nothing about what autism is. So just my character, I devoured everything I could find on autism from listening to podcasts, to reading articles, [A: to meeting people], meeting people, and chatting to them about that. That's just the way I'm wired, it's I was like I need to possibly can because I can see this it's gonna be a challenge for lot of different ways that we don't even know. So that's my recollection of when he was diagnosed and how we kind of dealt with it [R: yeah], yeah I just researched [R: yeah] Google is your friend.

R: Of course! And your enemy [A: yeah, yeah, yeah]. OK and did the way so that you viewed Tate, that you interacted with Tate. Did that change pre diagnosis and post diagnosis?

A: for me I don't I don't think so, but uh I would hear from Debs and them why they think he's doing this and then it really did help me figure out how to handle him better. Um like when he'd smash into to say hello like up here can you feel me. Yeah just wave and I'll know you here (R: laughs) but he doesn't do that anymore but that contact that he needed. So it just helped me figure that out and Laith also having done the research would go down and speak to him from there or mimic him and I would watch how he would engage more with Laith because he's mimicking him, so Laith he did the research so he connected. I don't care if he wants me to hug him or not, im gonna fricken hug him (R: laughs). So I push the boundaries a bit but yeah its just a way of learning how to be with him in those moments.

U: I think for me I think that was different, different post diagnosis uh because I wanted to try engage with him in the way that he needs to be engaged with, as opposed to the way Stace does it [A: I want to do it] like stop I'm different I'm like I wanna work with them yeah and make sure that he's always comfortable because obviously the tantrums that we're quite hectic to deal with. I think initially while we wouldn't understand what is going on [A: initially] yeah.

R: and L what kind of what kind of people did you speak to when you were doing your research?

U: so there was yeah she actually has a, [A: nineteen or something?], yeah he was much older so she'd had she'd had obviously had quite a long history of it and had a teenage boy and then obviously gone overseas trips and all sorts of stuff. So I can't even remember how…

A: there weren't any schools for him and then so she learnt the hard way.

U: How did I know her? That's the part I cant remember. Anyway doesn't matter. However I said can I meet you for coffee because I mean I've just found out that my nephews autistic and I wanna get as much information as I possibly can [A: you connect to Debs and her too, didn't you?] yes I did yeah [A: yeah for support?], yeah she said parents need support. So that was the only person that I can remember engaging with like directly [A: and Ronelle?] not so much. Just to pick her brain and so look he's just been diagnosed with what was the formative years like and then now flipside what's it like you know with a teenager and then dealing with hormonal changes and what what's that's like? So I think I was like maybe getting better ahead of myself but I just wanted to have a nice big broad picture.

A: It was quite hopeful for us [R: OK] so so I remember Laith with sharing with me afterwards and I was like if they can do it, then Debs and them can do it. And he was hectically autistic,was he? He was more than Tate.

U: yeah I mean I wouldn't call it hectically autistic but I would say he was probably more on the spectrum (R: laughs).

A: but uhm that's when I realized that it is doable back and you're not alone because you didn't initially feel a bit like that specially Debs and them.

R: What does the family dynamic like? [U: ours?], yeah when Debs told everybody, this is Tatey, he has autism.

U: yeah I think we just rallied around her. Yeah for us it was the case of how do we support you? Special needs sjoe! I mean we had good friend, who was Down Syndrome, Jamie. So we had that you know special needs kids. I don't really know anybody else that that that well.

A: The (family name) [R: yeah] yeah.

U: So we realize special needs came at a price for mom and dad and it also I think for me top of mind was also what is this going to be for Hannah? Because as a as a big thing yeah a typical sibling, like what is it gonna mean for her how and how is she going to navigate this? We've we've actually seen that though so we watched that and how she would take any attention even if it was bad attention she would take it, because she just wanted attention. So I hope I'm not getting ahead of myself but [R: no, no, no, no, no] but yeah so I think support was, was the key thing. How do we support you? What's the best way that we can help? And uh that's been harder than we thought it would be. [R: In what way?] To try and let them, let us help them. It's very it's been very hard for them to let us help them [A: yes].

A: because they don't want to burden us as they were feeling burdened.

U: So I think for them and then think that oh my word, our child is so hectic we cannot have like put this on other people [A: cannot yeah] when when I think our perspective was we know how hectic this must be for you so let us take some of that stress or …[A: you'll end up in hospital] or your worse you'll end up divorced.

R: So what was that journey like when did they start letting you help?

A: Actually only, after the last id say couple years really initially, they took like an hour to explain the handover and we'd have them maybe there for an hour [R: yeah].

U: I think I think it it's been a slow process but I think initially they didn't really know how we could help them because there was obviously like it's they were figuring stuff out for themselves, so for us it was just initially I think the easiest thing was to say we'll come to your home and you go to our home and we'll just do house swap. We'll stay at your home and we'll be in comms.

A: even other day when they went for Jonno's Christmas thing, they just left and L like they just left and Debs is phoning you S (R: laughs). I say whats up? Please switch the balcony light on… Debs...Please don't phone me… my worst thing.

U: I think I think initially it was hard for them to to figure out how to let us help but I think as we as we did it and then it was like sort of being with them and helping Tate, come into their home and just you know Debs would be fussing, Stace would be upset

A: Laith and Tate were good and I focused on Hannah. [U: it was kind of the easiest to do] its still kind of although I think Tate likes me more now I don't know why (R: laughs)

U: its just a phase

A: he said goodnight to me the other night [R: aww]. He voice noted me shame.

U: uhm theres your phone. That looks like a DA or something [A: no, it might actually be the Coricraft, sorry]. A leaves to take a call.

R: Go for it.

U: uhm so I think that's how we helped, like we went away with them [R: yeah]. Yeah we took a family holiday so we could just to kind of take the pressure off them so if they wanted to go and have some husband and wife time we could take the kids and just entertain them while Debs and Jonno actually just relax [R: yeah] I think it was also like a phase for them to learn that they could actually trust us with Tate specifically, obviously they knew, cause we've taken Hannah and it was fine. But I think it was hard for Debs and Jonno to to let other people [R: yeah] look after Tate [R: yeah] they were just so nervous.

R: hundred percent. Jonno actually said something so interesting when he was telling the story about how they got the diagnosis for Tate it was such a fleeting comment but one of the things that's really stuck with me for their interview he said when they were learning about autism, you know they took it on themselves because they couldn't, they couldn't they obviously couldn't put it on the family to understand what was happening. So I asked him why but why not because these are your people that are like your support system like why could you not expect that I was there because knowing John or Debbie they are the people that would do that for other people, so why could you not ask your family to do the same for you? But he was just very much like it was our burden

U: so he didn't actually give an answer he just kind of

R: he just said it was but it was it was something that they were going through as a family and they couldn't put that on anyone else which is essentially what you're saying now.

U: I think they all still a little bit like that I wouldn't say a lot which is, its just who they are.

R: 100%, I think I see it in Debs as well like I mean Tate comes to Khanyisa and sometimes she'll have work to do so he'll stick around and she's still like guys is it OK if Tate is here? But I was like Debs he belongs here more than anybody else.

U: yeah we just worked within that we can we can only take as much as they'll give us and so we've just been there we need to take whatever they'll give us [R: yeah] for us it's not enough I think we could have them more (R: laughs) but but yeah we we we we get stoked when get a weekend and now it's like weekends [R: yeah] but you can literally take them for the weekend they come for sleepovers and it's incredible.

Aunt returns

A: the only reason we don't have them around more often would probably be because L's got worship at churches in the band and I sometimes am coordinating duty up there. So what we have a thing in the in the evening but we do know they love to plan ahead as well and then we go right and I'm not doing anything this weekend we got the kids. But it doesn't happen often enough which is I'm waiting to get their bums back from the beach house so that they can come here.

R: it looks amazing so obviously we've known Tate at Kanyisa since he's about 2 1/2 maybe and to see him from what he was there to what he is now has been just the most incredible change.

A: we noticed that when you started going to Khanyisa [U: like within a year] like that. When you started going blue, orange, like what, you know colours! We were like wow!

U: and we remember the fireman videos and all those

A: it was like incredible, we were like wow! And I actually said to Debs you know what actually got normal, amazing kids get out of the uhhhh mode and realize that they're actually fine. They're not gonna stick their finger in the dogs bum anymore (R: laughs) [U: well…]

R: on occasion. Yeah so it's like with this beach house weekend that they had she sent us some photographs to our group of him holding a crocodile and he he sent us a voice note, Amy, Tammy, Teacher K, Pri, Christine, I just I was holding a crocodile and telling us this story it was so cute but obviously that that's something that's so new [A: yeah] for them to be experiencing. I mean even I think when Debs last went to Ballito it was maybe a year or two ago and they didn't venture out as much. She just shared that you know they went out they went to multiple places one day and then they also went out to eat but there was nothing gluten free and so then Tate had his snacks but he didn't complain. He ate his stuff and he didn't get what Hannah had and he was OK with it and I think she was just quite blown away by that which is amazing.

A: We've noticed as well, I've picked up, because we're getting this it and Tate's got fricken that [R: his rice cakes] and Laith going baby don't mind and im like surely we can't juts … Tate doesn't mind with food he would rather not feel sick.

R: yeah 100% which is the most amazing really amazing. Yeah anytime you like comes here something that he looks like he might want. He will ask you if its got gluten? Yeah so knowing Tate then um like there were stories that we see in like our IDP meetings and stuff about how you know. The one story I remember very vaguely was they went to Moses Mabhida stadium and it was just absolute trainwreck, Tate wanted to be everywhere, go everywhere and do everything and couldn't stop. Yeah so even like those things like I remember them saying no we had to leave it was just too hectic and there were lots of people that were judging, and looking and that kind of thing.

So as people who like embrace inclusivity, what do you think makes an environment inclusive? And it's not it's not an environment specific to like a coffee shop or a shop, like in general, what did we think community to make it OK?

U: Educate. Just simply educate people so that they understand. Because until I looked I wouldn't have understood, I would have seen a tantrum and kid in a centre and immediately thought oh he just needs a good hiding. Those parents don't know how to parent.

A: 100% even I've had a few kids screaming and going nuts in trollies, and I look and I'm going you can tell the difference between a naughty kid or someone that's got the issue. And we, we didn't know, I

wouldn't know. My parents still struggle with it [R: in what way?] they think he's he knows right and wrong and he's just naughty. He just does it but maybe he might push boundaries but it's OK, that's what all kids do. He might push with them [R: 100%], but I said to mom just explain that why you say no because every time you come you just go, no, no, no, no, so you know they're not that bad.

When they're with us like frikken angels (R: laughs) even when they were with Jonno and Debs was overseas. My parents said they never heard the kids they were the best. When Debs came back everything went back (R: laughs).

U: that's typical children [R: absolutely], yeah so when the cats away the mice will play. I honestly believe that especially for differently abled kids so that people can just be educated as to what some of the signs are that you can see that that kid is tantruming and not you know having a meltdown. Theyre having a meltdown and not just being a brat. There are a couple of things that you could maybe and then pay attention to the parents so it's just the education to watch those things and then and then have a little bit of compassion to go and say hey like can I maybe just hold your parcels while you you know, little things like that but you can just actually be part of the solution instead of staring and gawking like everybody else [R: yeah] otherwise parents are forced to wear a T-shirt like my child is autistic can you give me a freaking hand [R: yeah] on the back or something [R: yeah 100%] yeah please don't laugh and point.

A: I do love that UK idea of you know, here if you wear the whats it? A red ribbon, its HIV. If you wear the pink it's cancer everybody knows that. So to have something like that where everyone is educated yoh it will make such a big difference. I think one more kids nowadays are have the issues are more obvious and people treat them [R: yeah] with back in our parents days half of them probably had stuff but no one knew how to deal with it. And so they were just pain in the butts.

U: With education, the tools on on what to do, so understand what what the challenges are and how you deal.

A: People are more open to that stuff nowadays, they don't frown up on anymore. People are becoming more inclusive, I think. Slowly but surely. But its being in front of them is important.

R: And do you think that education um do you think that that needs to look like adults being educated or adding it into your curriculum when children are learning how to interact with differently abled kids from the beginning or?

A: I don't think there would be harm to teach kids from the very beginning. I mean it might even help us with bullying uh whether your school has disabled kids or not. Everyone comes across at some point.

U: That's quite a deep question like where you start? [A: at hospital when they're born] (R: laughs). If it's the case of the school that's good to be like like building compassion [A: in LO], I understand people are different to you and that's OK. You know so there's that side of it but there's also like like how far can you approached in the home and said like hey mom and dad you know like just when you bringing your kids up you need to also teach them these things and people are different so they don't just get it at school but they get it at home.

A: Well they are doing it already with the LGBTQ thing they're bringing that conversation in so why can't they bring disabilities?

U: that's what im saying I think I think parents because of education and access to information are having are able to have better conversations with kids whereas our parents were like from war torn veterans (R: laughs), one thing belt [R: yes] or bed with no dinner that was like the idea [R: corporal punishment]. Especially for autism cause it's so nuanced it's so like this it's such a wide spectrum that you go non-verbal and people that I mean with Tate the other day didn't even realize that you were in the bathroom and we washed our hands and it's gonna put the air thing on and he was like ahhh and I was like oh my word im so sorry [A: and you couldn't switch it off] yeah I could switch it off and he was freaking out. I was like that was a perfect example of someone who knows them all that didn't know about that that's like an obvious thing I still missed it yeah and then you have to kind of bring the freedom I think to to people to say look you're gonna get it wrong and that's OK too just as long as you learn from it. Like guess who never uses air dryers now at the bathroom?

R: I think that also brings an important point to that even like with that education there's still like they're also that physical changes that we can make to environment sometimes I think that the main thing when people think disability is like is there a wheelchair ramp like [A: physical] physical [A: yeah] but there's nothing really for like the sensory kids like Tate there's no option for to go to bathroom with that that that isn't there [U: that's not gonna happen].

There are a few places uh I think there's only like one or two in South Africa that do it but they have this thing called sensory hour and so basically in like at grocery store they will dim the lights, they will stop the music, [A: oh that's lovely] they you know they'll put on like calm music or and they'll limit the number of people that come into the shop. I think there was actually a Spar in Cape Town or something.

A: shopping was a huge thing for Tate actually, so yeah I would like I'd go to that shop even if it was in Umdloti or Ballito.

R: Yeah, yeah and all it takes is one hour they only do it for one hour a day and not necessarily everyday but I imagine such a game changer for people to come in or for families to be able to access that, know that it's overwhelming experience because it can be. There's a million people talking and then there's Christmas music playing [A: so many things to look at] so many things to look at so yeah just that like that physical thing too is something that I think about amazing.

A: still need the paper towels in the bathrooms [R: yeah] costs more but hey.

R: in the long run its more inclusive. So Tatey yeah so obviously like the shops were a big thing for him and now like Debs can take him [A: his very good in the shops now] yeah its really amazing.

A: I like to push Tate [R: tell me], it's terrible but I like to I don't know what it is. See Laith finds it like [U: unncesscary] (R: laughs). But I like to put him in a position where he needs to make the right choice you know what I mean and so like it's just a hug so we frikken give me a hug.

U: And that feels like razor blades, you know when you have to sit at the table and finish your oats (R: laughs).

A: oh yeah, yeah, that's terrible but I just like to push him [R: why do you do it?]

U: Sadist! Sicko! (A & R: laughs)

R: I can see it comes from love.

A: yeah yeah but I think it's maybe it's because he is so the other way that I like to keep that balance and just I mean like it isn't like razor blades [U: no], it's it's sometimes you gotta just put up with somebody that uncomfortable sometimes you don't like hanging with people because they're lame but they like being with you. You just have to do it and we all have those things so just because you have a disability sometimes you must just try.

R: yeah I mean he said you know could be a workplace one day and he's talking like all his colleagues necessarily or they're not always gonna understand him it's like a maybe

A: that's why I'm that guy.

U: Toughen him up. (says it sarcastically)

R: what it is what do you guys see Tate doing one day and I asked Johnno and Debs this question but they said it's very difficult for them to dream they're a bit too afraid.

A: that's a very responsible answer I'll just blatantly tell you he might be a Russian freaking developer or something (R: laughs) [U: Astronaut]. No I mean something to do with aircraft for serious countries.

R: Building or flying or?

A: Building probably [R: and test flying] but I don't think he necessarily enjoys flying, he enjoys sitting, he enjoys the mechanics of it [R: that's a good one].

U: Yeah that occupationally [A: maybe design cars for Mercedes or whatever] I find that one a difficult one to answer just because of like I'm not sure how much he can you can do yet and I don't mean that to sound in a horrible way but like I know what goes to job like I don't see him packing bags at the Checkers but also don't see him like managing a team in a corporate you know so [R: yeah] and like there is so much in between there like so I think occupationally I found that one hard. I'm still back on the fence [R: yeah] where I see him finishing but I do believe he'll be able to work and earn an income I do believe that, what I don't know? But sideline I see him being a drummer [R: yeah, yeah I agree with you] [A: for sure].

A: he will just storm off the stage when his done.

U: throw the sticks and walk off . Soo like musical, his definitely got time and rhythm. The fact that he goes do,do,do,do,dah, on the drums.

A: that's insane, he just watches and he does.

U: he can pick up stuff so quickly. If he can pick up stuff so quickly that leaves him loads of things he can do. Yeah I don't know but yeah that's what I see.

R: Do you think for him girlfriend, wife, living independently [A: that poor girl] (R: laughs).

U: I definitely see that I mean love on the spectrum kind of opened my eyes to that I was like those owkes are totally keen to be with somebody yeah want to share life with something.

A: and they learnt how to deal with the awkwardness that they need to push through and yeah I love it.

U: I mean those dates were histerical (R: laughs) [A: so good].

R: dating is hard at the best of times but have that like extra thing.

A: I've been curious to see him find someone because he does get fond of people very fond I'd be curious to see him find that girl that's his age that girl he goes, I actually can't stop thinking about it now I'm curious to see that happen and then how I think you will go the extra mile to just how he goes the extra mile to not get sick and have that feeling. I think he'll go the extra mile to make someone feel OK I think.

R: Do you know what's actually hilarious there's a there's a girl on his class now Danny um and she is quite she's quite auditory sensitive but to see her and Tate interact is my favorite thing because there's a certain sound that he makes that she doesn't like but he'll like he'll look at her and he'll be like (R: clicks tongue) and then she's like and then you'll do it again and then she'll come over and then she'll be like cross at him and he's like. Like typical like you know when you meet a girl you like pulling pigtails like [A: that love hate thing] it's very very cute.

U: Yeah I don't know I mean I know obviously the like the sexual side of it obviously intimacy and and and I know Debs has just mentioned her concerns about you know Tate having kids and is that possible? What does that look like? Are they able to live on their own? Geez ther must be a gazillion questions that go through her head. So I don't know whats that going to be like. I don't know much about that. Love on the spectrum gave me huge hope for like relational stuff whether they multiply or not (R: laughs) we don't know but yeah but certainly him able to do something like that.

R: I know Debs, where she's struggling to like think so far in the future and also we don't we don't have the same kind of services that other places necessarily have like there are some countries that have it's not what it's a little bit like assisted living but not quite.

Like you live in [A: sorry] no go for it. You live in like a dormitory and you live with other people who have disabilities and there's someone like in charge of the floor of like say six people and budget with them [U: okay] it's like a transport for the home and drop you off your driving your job and then they fetch you or they give you a bus schedule and they teach you how to use the bus. So I can totally understand why it's difficult for her to imagine what his future will look like when we don't have things that would probably help him.

U: yeah that's why its first world countries. They just have stuff that works and people that don't freakin steal the money (R: laughs) is it going to them?

R: let it go where it's needed. Yeah so that so that's basically where my my dream is for us it's like have those things that are just put in place that make it less stressful for families that

A: im so sorry I have to go

R: Do you have to go

A: Ill see you. L can probably answer way more honestly and maturely than me.

R: That's so fine, thank you so much I've only literally got like one more question so don't let stress.

A: do you want to ask me quick?

R: of course so my last question is. So what role do you think children who have different needs play in our society at large and if you want to answer within your community specifically?

A: I mean I get so encouraged by being at Khanyisa or with it by hanging with Tate taking him to church I'm actually proud. Even though he totally interrupted the preach once but people can learn so much from him. We do. So I would definitely frikken make way for something, somehow. Love you guys.

R: Bye Stace.

A: Bye.

U: I feel that they they help us break molds so like if I think about the example that Stace is talking about where Tate. So he's fixated on obviously drummers that's how he wants to the drummer and it's like dude you can't go and see the drummer right now you can go afterwards and then he was sitting at the back telling me how he also wants to speak like our pastor was speaking in the front. Like I wanna speak like that. Yeah you can one day and he was getting up to go and I was like no, no, not now (R: laughs) not now [R: one day].

And that same day he went down to the middle it was like while Greg was busy preaching and stood up and what's amazing is if you're sitting there and that's happening like with Jeremy obviously we've had Jared and you know he's been in our church for a while and he went and he's come back on but he was way more disruptive initially and you just have to look around and you can see that there's a lot of people that get it but there's more people that don't and so I think what that does allows the more people that don't to recognize and go oh OK so this is not something to stand there judge and wag my finger at but to be able to go and like it's OK cool he's also a member of our community he's not he's not separate from us because he has a disability. So if he wants to voice something everybody say yes Amen yes we agree yeah why can't Jared do it? Why can't Tate walk up to the front and say hey I wanna preach one though [R: yeah] might be the wrong timing [R: yeah] might be out of the norm [R: yeah]but has it really made a huge difference in the message, everybody like now doesn't know what's going on in the message or is it just the moment we've been OK cool we get it it's 30 seconds of your life people, its not the end of the world. We all will sit down and carry on so it just helps break that mold its ok if something doesn't go exactly according to plan. We sing our three songs, we sit and he speaks and we go and you know just break that routine sometimes. So I think they have a huge part to play in the end to help us see the world differently. Yeah I think it just you know just keeps us keeps our empathy high, keeps our our thoughts of how how other families have these challenges and you know you come home to pigeon pair and everything's nice and cozy. You've got your white picket fence and everything great. There's a lot of people out where its not like that so just to keep your mind like it's more than just our yeah if it works.

R: yeah and I think that for me that working here at Kanyisa you never know like sometimes a parent will come in and they will absolutely crap on you for something really small but oftentimes it's never really about you and I think that like that is something that I take into everything that I do because there's always something happening in the background of somebody's life that you never get to see [U: there's a story you don't know]. Yeah as you said so I agree with you on that. Amazing. Thank you

U: Cool. You know geez, kudos to you for doing what you're doing. [R: thank you]. Its people like you that will make the difference that just makes [R: I hope so] everybody elses lives a whole lot easier (R: laughs).

R: I mean that's the dream. That's the plan.

U: Yeah.

R: Amazing.

Appendix D - Pilot Workshop Resources

Ncebsi's Story

She is ~~Monster~~ Aliza

Ncebsikazi Dotwana is a World. A Divine ecosystem. She is a daughter of Bizane, Legacy of the Dotwana name. If Ncebs is a planet, then Aliza is the sun. She is the dazzling centre of Ncebsi's orbit.

Ncebsi carried the weight of the world on her shoulders since entering it, weighed down by grief and abandonment. Clothed in potential and possibility, her centre of gravity shifted from future breadwinner to unplanned ~~and unblessed~~ motherhood. She was their hope, their future. She completed matric and she would have changed the family's tides. Struggles were the family's every day and Ncebs was *supposed to be* the solution.

It was hard to accept that the trajectory of her future was changing before her eyes. And yet, She couldn't wait to meet her darling daughter.

~~Their curse~~. Her **blessing.**

~~Their shame.~~ Her **pride.**

Her **sunshine**. ~~Their darkness.~~

Her **warmth.** ~~Their wrath~~.

A mother's love wider than the ocean, warmer than the desert, beset by…

"Come back next week."

"She's still small."

"You are being punished."

"We don't have any beds available."

Prophets put price tags on miracles and white coats turned a blind eye. It took Aliza 3 days to open her eyes. Despite the doctors' best efforts to placate Ncebsi, her maternal instincts spoke louder than the medicine. Panic clawed at her. She knew. She knew. She just knew. She knew something was wrong. She knew. They refused. She knew. They ignored. She knew. They rejected. Help never came from anyone. Just Ncebsi's fierce determination.

It was | Ncebs and Aliza | against the world. This lonely path, this pursuit for answers, was paved on a looooooooong, winding, tumultuous road.

Commented [RM1]: This reinforces her mother's pride in her.

Commented [RM2]: We have incorporated world/nature metaphors throughout.

Commented [RM3]: All lines scratched out is what was said about and Aliza but that are not true for her.

Commented [RM4R3]: This also true of the grey phrases.

Commented [RM5]: This shows how small she felt struggling for help, but also how she built herself up on her own.

Commented [RM6]: The lines | | show that they are a unit.

Commented [RM7]: The path was paved on not by because she was met with multiple obstacles that were in her way, that often times tried to squash her spirit.

A journey, cemented with uncertainty, seclusion, questions, and loneliness. Walls and waves of denial and disregard. And yet, taking this difficult road was the easiest decision Ncebs has ever made, because it was for her Aliza.

You see, this story is not about grief and sorrow. It is a love story between mother and child. A mother who searched for answers, no matter what. A mother who believed. A mother who believes.

Nevertheless, she persisted.

Off she drifted [with all her baggage and burdened with great purpose] to an urban jungle where she also felt unsafe, because the best of her was **u n w e l c o m e.**

"Look at that monster!" "Look at that monster!"

She heard and felt the disdain, in hushed and loud tones. *That* monstrous *"child"*. Who simply existed, wrapped in a chrysalis of her mother's love.

Even mundane moments were sometimes plagued with stares and comments. Walking. Existing. Breathing. Shopping. Her warm radiant sun was followed by a ~~little girl~~ shadow in the aisles. As Ncebs compassionately extended an olive branch, she was greeted with tears, fears and a mob with proverbial pitchforks – the patrons and staff alike.

"She is a scourge."

"She is a monster".

"She is scaring *my* child."

"Why would you bring *that* child here?"

Adorned with the void of family and ancestors, Ncebs optimism butterflied - set free, reborn - with the desire of belonging for her Sun. Even darkness was feeble against sunshine and so slithers of kindness began to shimmer through the echoes of "monster". She was now clothed with resilience [code for dignified suffering] and yearning for gentleness.

Commented [RM8]: It started at birth hence cemented now as she ages.

Commented [RM9]: It has been a negative experience for her and yet she is not negative about it.

Commented [RM10]: The baggage was both Emotional and Physical – It was her starting over.

Commented [RM11]: Style for emphasis.

Commented [RM12]: Some didn't care what they said or how it would affect their family. Whether whispered or shouted, both caused pain.

Commented [RM13]: The quotation marks are here because that's how she was perceived: "less than", "not quite".

Commented [RM14]: The word is glowing because Aliza is sunshine and her mother continues to see potential for her. It also links to the butterfly analogy.

Commented [RM15]: One day, Ncebs and Aliza were shopping when they were followed by a little girl who was unkind to them. She was an innocent little girl but the way she behaved cast a shadow over their experience.

Commented [RM16]: This is another nature analogy.

Commented [RM17]: This is a powerful and well known image.

Commented [RM18]: That – It is a term that can be very "othering".

Commented [RM19]: This reinforces that she lost her original community and part of herself.

Commented [RM20]: This emphasises that she is always hopeful and that she just wants the world to see how truly special Aliza is.

Commented [RM21]: This is a contrast for imagery.

Commented [RM22]: Not all strangers are cruel to them.

Commented [RM23]: Refers to what people see on the outside and not always what's going on underneath.

Commented [RM24]: The world will praise her resilience but never step in to help her.

And hope arrived, from ~~her community~~ strangers brimming with kindness at a taxi rank, in the queue. Unnamed humans whispering encouragement. Could mundane moments be beautiful again? Strangers lifted the weight of the world slightly. Ncebsi's sun was as luminous as she knew and now, she wasn't the only one to see it.

Commented [RM25]: Her community is not the conventional/typical community. It has been redefined through her experiences.

Commented [RM26]: Reinforces the idea of belonging that she longs for.

Commented [RM27]: Contrast to the incident at the shops.

Commented [RM28]: Some faith restored.

Pilot Workshop Questions

- What are your thoughts on what you've just read?
- Did this story impact you or not? If so, how?
- What stands out for you?
- As a therapist, what have been your own experiences of working in communities?
- What do you think could be different about how we practice? (How we serve families, how we serve communities, how we make therapy accessible, how we share the burden, how we create inclusivity).
- What changes do we need to make to get there?

Appendix E – Final Workshop Pack

Introduction

Hi _____

Thank you for being part of this workshop. Over the past few months, I have been interviewing families who have neurodivergent children in order to understand their views on inclusion and belonging in their communities. Each family had layers of intersectionality – whether it be race, religion, socioeconomic status or how visible the disability is. The stories I collected have all deeply impacted me in different ways.

In this pack you will find:

- **The story of Ncebsi and her daughter Aliza in the form of a narrative:** I believe stories hold immense power to move people to change. With the help of my supervisors, I have crafted a narrative based on my interview with Ncebsi. We have used a combination of visual, written and editorial creativity to bring her story to life with the hopes that when people hear it, they are enlightened. I would love you to read it and share your thoughts. You are welcome to write, highlight, debrief (on the notes page) and otherwise do what you need on these pages to process what you've read. You will also find some reflection questions after the story to guide you on this journey.

- **Background to their story:** This is an important piece of the puzzle that helps contextualise the narrative and gives you a little more information around Ncebsi and Aliza's journey.

- Reflection Questions: I would love you to answer these before the session on Saturday a your reflections will be the springboard for our discussion

- **Food for thought:** On this page you will find a few quotes that I found regarding inclusion and community. Have a read, have a think!

- Notes pages: For scribbles and ideas and important realisations.

Workshop Agenda

9:50 – 10:00:

Arrive, settle in, make some coffee, grab a snack.

10:00 – 11:15:

Sharing of story reflections and discussion around community/inclusivity

Interview Clip of Ncebsi's Interview with discussion

11:15 – 11:25

Toilet Break and stretches

11:25 – 12:00

Food for thought

Reflection Questions

1 . What does community mean to you?

2. What does inclusion mean to you?

3. What does inclusion in the community look like for you?

4. What are your thoughts on this story?

5. What do you think it was about the institutions that Ncebsi mentioned that made them inclusive or exclusive? Was it that everyone was educated and if so, how does that impact her interactions with doctors (highly trained) vs strangers (who were kind)?

6. Where do you think within your profession, you could fit in to this story to help Ncebsi and Aliza in their community?

7. When it comes to working with and embracing community when planning intervention, how do you think we get there and why aren't we there yet?

8. What do we need to do to change this?

Food For Thought

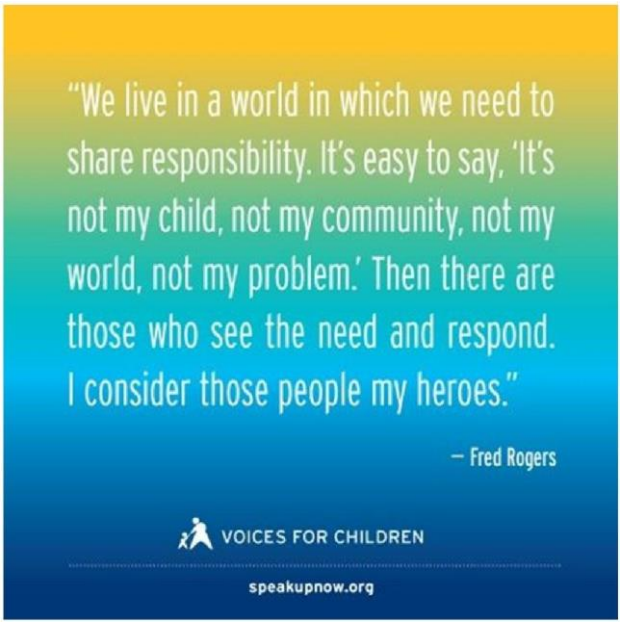
There's a heaviness that comes with parenting a child with a disability.

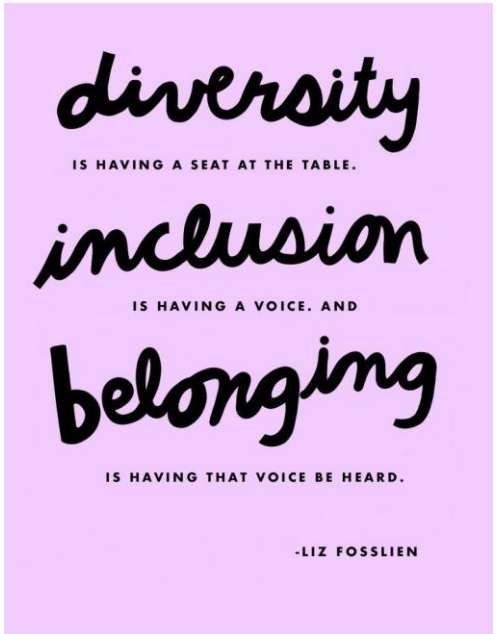
It's not sad that my child is different. It's certainly not shame. Nor is it a burden.

@jillianbenfieldblog

The heaviness is a longing for what he longs for- to belong just as they are.

Jillian Benfield





Thank You

This project would not have been possible without you. Thank you for your willingness to share, to dig deep and to get uncomfortable. I so appreciate you stepping on board this rollercoaster that unsettles and unlearns and relearns and takes you on a truly wild ride. I appreciate you so much.