

Understanding Autism Spectrum Disorder in Context: a comparison of family perceptions in a high-income and low/middle-income country

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requirements for the degree of MSc (Med) Neuroscience

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ABSTRACT

Background

Autism Spectrum Disorder (ASD) affects individuals from all continents, cultures and socio-economic backgrounds. It presents differently in different individuals and functional outcomes can be highly variable due to the heterogenous nature of ASD. The context or environment in which individuals live interacts with the core characteristics of ASD to determine functional ability or disability. For this reason the World Health Organization International Classification of Functioning, Disability and Health (ICF) includes environmental factors when measuring and describing functioning. ICF core sets for ASD were recently developed, and included a qualitative study with perspectives from five highly divergent countries (Canada, Sweden, India, Saudi Arabia and South Africa). It is, however, not known whether functional themes in these diverse environments were similar or different. We hypothesized that environmental factors would predominate in low-resource settings where they would be perceived as barriers to functioning.

Objectives

The purpose of this study was therefore to examine the association between context and functional ability/disability in children with ASD. We aimed firstly, to understand the global landscape of parental perceptions of functioning in their children with ASD. Secondly, we set out to compare and contrast parental perceptions of functioning in two of the most divergent countries that participated in the ICF core set development study. We were interested in the frequency of functional items reported by parents/caregivers from a high-income country and a low/middle income country. We were also interested in the content of the functional items reported by parents/caregivers in these two countries. We selected Sweden as example of a high-income country (HIC), and South Africa, as example of a low/middle-income country (LMIC).

Methods

To meet the first aim, we performed a scoping review. Two researchers conducted a comprehensive search of peer reviewed studies published between 1990 and June 2016. Full-text of all included articles were accessed and summarized using thematic analysis. Key findings relating to the scoping review question were linked to ICF-CY first or second-level categories. To meet the second aim, we performed secondary analysis of qualitative data from the ICF ASD core set study. Using frequency and content analysis we compared South African (n=22) and Swedish (n=13) participants. The identified ICF-CY categories were ranked and compared for similarities and dissimilarities in frequency of reporting and analyzed for similarities and dissimilarities in the content of themes.

Results

Thirty three studies were included in the scoping review, and most were conducted in HIC (n = 25/33, 76%) with only six studies in LMIC (n = 6/33, 18%). Two studies compared perspectives from LMIC and HIC (n = 2/33, 6%). Functional themes from HIC included a range across the ICF bio-psycho-social framework with body functions, activities & participation, environmental factors and personal factors all represented. Functional themes from LMIC were predominantly focused on environmental and personal factors. We did, however, acknowledge that different methodologies may have biased findings in HIC versus LMIC.

Secondary analysis of the ICF ASD Core set qualitative study therefore used data collected in identical manner in South Africa and Sweden. Complete frequency agreement was seen in 4 ICF categories in the two countries - three activities & participation categories (carrying out daily routines, dressing, complex interpersonal interactions), and one environmental factor (immediate family). Obvious differences in frequency of reporting were observed in one environmental factors category (health professionals), six body functions categories (e.g. involuntary movement functions, gait patterns, basic cognitive functions, and mental functions of language), and three activities & participation categories (managing one's own behaviour, speaking, and undertaking a single task). Only three ICF

categories (immediate family, attention functions, products and technology for personal use in daily living) differed in content between South Africa and Sweden. Two additional categories were identified namely health professionals and sensory processing.

Conclusions

Contrary to our hypotheses few differences in parent/caregiver perspectives about environmental factors relevant to functioning in ASD emerged. Perceptions more frequently differed regarding body functions and activities & participation. The content of perceptions were, with a few exceptions, similar. Our results suggest that the interaction between context and functioning is more complex than we predicted and highlights the importance of subjective perception of contextual factors in relation to functional ability/disability. Given the universality of findings, our results therefore support the global usefulness of the recently developed ICF core sets for ASD. We recommend that more comparative studies on ASD and functioning should be conducted, and that similar comparisons in other disorders where core sets have been developed, such as ADHD, may also be of value.

Keywords: ASD, ICF, LMIC, HIC, functioning, disability, parent, caregiver

Abbreviations

- ASD Autism spectrum disorder
- CINAHL Cumulative Index to Nursing & Allied Health Literature
- G Global data set
- HIC High-income country
- ICD International Classification of Diseases
- ICF International classification of functioning, disability and health
- ICF-CY International classification of functioning, disability and health – child and youth version
- LMIC Low/middle-income country
- S Sweden
- SA South Africa
- WHO World Health Organization (WHO)

Key Terms

- Autism spectrum disorder
- Contextual factors
- Functional ability/disability
- High-income countries
- International classification of functioning, disability and health
- Low/middle-income countries
- Parent/caregiver perceptions

CHAPTER 1

Background to autism spectrum disorder and functioning in context

1.1 Background to the thesis

This thesis will explore the impact of context/environmental factors on the functioning of individuals with autism spectrum disorder (ASD) in two obviously different socio-economic settings, as seen from a parent/caregiver perspective.

Perspectives from Sweden as an example of a high-income country (HIC), and South Africa as an example of a low/middle income country (LMIC) will be compared in order to identify similarities and differences between functional themes presented by families in these two settings.

Chapter 1 will provide background information on ASD, functioning in ASD, functioning in context, parental perceptions of functioning, and the International Classification of Functioning, Disability and Health (ICF) as a framework for functioning. It will also give an overview of the overall design of the study. Chapter 2 will present the first phase of the study which consists of a global scoping review of parent/caregiver perceptions on functioning. Chapter 3 will present the comparative study between South African and Swedish perceptions of functioning, and chapter 4 will provide an overall conclusion of the study.

1.2 Autism Spectrum Disorder (ASD)

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (American Psychiatric Association, 2013) identifies autism spectrum disorder (ASD) through impairment in two major domains, namely (1) social communication and social interaction in multiple contexts, and (2) restricted, repetitive patterns of behaviour, interests, or activities. A variety of functional

areas are impacted due to the fact that signs and symptoms vary in severity and ASD present differently in different individuals (Mandell, 2011). Existing evidence suggests that ASD is a result of the complex interplay between various genetic and environmental factors (American Psychiatric Association, 2013), but the exact nature of the aetiology or aetiologies of ASD is not yet known.

In the United States of America 1 in 68 children have been identified with ASD according to estimates from the Centre for Disease Control and Autism and Developmental Disabilities Monitoring (ADDM) Network (Centres for Disease Control and Prevention, 2017). ASD was reported to be about 4.5 times more common among boys (1 in 42) than girls (1 in 189), and to occur in all racial, ethnic, and socioeconomic groups (Centres for Disease Control and Prevention, 2017).

There is an increasing volume of ASD-related research from high-income countries (HIC) such as the USA, UK and European countries. In contrast, a very small proportion of ASD research to date has come from low- and middle-income countries (LMIC), even though approximately 90% of individuals with ASD live in LMIC such as in Africa, Asia and South America (Kieling et al., 2011; Franz et al., 2017).

In a recent scoping review of ASD in sub-Saharan Africa, Franz and colleagues (Franz et al., 2017) identified 120 peer-reviewed articles from sub-Saharan Africa and 121 from North Africa in comparison to 11 569 articles from North America and 7 577 from Europe. Given that most people with ASD live in LMIC it seems essential to increase the focus on research in these regions to understand and address ASD globally.

1.3 Functioning in ASD

ASD not only presents differently in different individuals but developmental and functional long-term outcomes are also different (Howlin and Moss, 2012; Howlin et al., 2013; Szatmari et al., 2015). While language skills and IQ seem to be strong predictors of functional outcomes (Magiati et al., 2014), little is known about other factors that can explain variability in functional outcomes for children with ASD. Szatmari and colleagues (Szatmari et al., 2015) suggested

that ASD symptom severity may not necessarily be a predictor of functional ability and that less or more severe autistic symptoms do not result in higher or lower levels of functioning in ASD. Although data suggests that there is a link between ASD symptom severity and functioning at a specific point in an individual's life, longitudinal data suggest that change in one domain such as symptom severity for example, is not necessarily associated with change in functional ability over time (Szatmari et al., 2015). Gaining more insight into functioning in ASD, especially in under-studied population groups may enable a more appropriate and nuanced understanding of clinical and service needs, intervention strategies, policy and funding requirements, and to monitor health/education system changes more appropriately (World Health Organization, 2007).

Functioning can be defined as an individual's performance of daily activities required to fulfill their occupational roles such as worker, sibling, friend, learner or employee (Baum and Edwards, 1995).

Several conceptual models of functioning and disability exist. Examples include a 'medical model' which views disability as a condition "caused by disease, trauma or other health condition" (Wade and Halligan, 2004). This model requires management of the health condition and the individual who presents with the condition to change in his/her behaviour through medical care, most often in the form of individual interventions provided by professionals. The 'social model' of disability views disability as a problem concerning the individual's integration or lack of integration into society. This model sees disability not as an attribute of the individual, but rather as a problem created by the social environment, a problem that is the responsibility of society and that should be managed by societal action through the necessary environmental adjustments that will enable those with disabilities to participate in all areas of life (World Health Organization, 2007).

The 'biopsychosocial model' is a combination of the medical and social models. This model views functioning as the "interplay of abilities and disabilities that emerge in the contexts of physical constitution, social participation, environmental resources and personal resources" (Engel, 1977; Borrell-Carrió, Suchman and Epstein, 2004; World Health Organization, 2007). Figure 1 demonstrates how the different components of the biopsychosocial model interact and contribute to the impact on functioning.

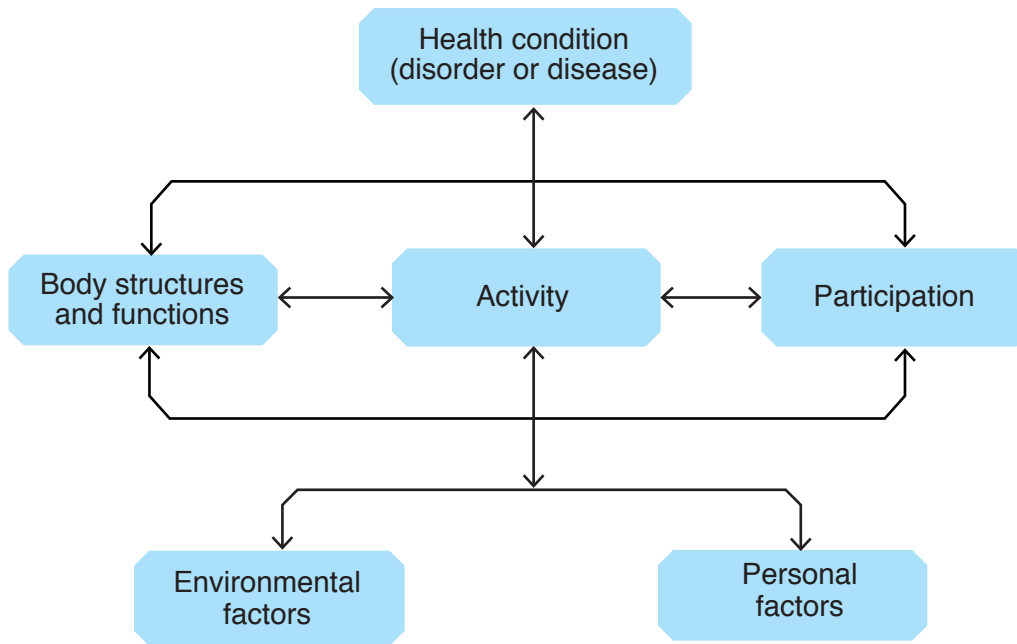


Figure 1.1 The biopsychosocial model of the International Classification of Functioning Disability and Health (World Health Organization, 2007).

For the purpose of this study we will use the biopsychosocial model as the theoretical framework when referring to functioning given that the model allows for the combination of clinical symptoms of ASD as well as contextual or environmental factors to be considered in an interactive way.

The biopsychosocial model is also the model used by the World Health Organization (WHO) to describe functioning in their International Classification of Functioning, Disability and Health – Children and Youth version (ICF). The ICF will be discussed in section 1.5.

1.4 Functioning in context

Little is currently known about the possible role of sociocultural factors, race and ethnicity on the manifestation, treatment and outcomes of ASD (Daley, 2002; Wallis and Pinto-Martin, 2008). Even in HIC racial/ethnic minority families are significantly underrepresented in research (Wallis and Pinto-Martin, 2008). This may limit the generalizability of findings (Ratto et al., 2016) and our understanding of the complex interplay between genetic, environmental, socio-cultural and other factors (Sotgiu et al., 2011).

A better understanding of ASD across different environments/settings may help us to determine the suitability of clinical tools and strategies in low-resource settings, and may indicate the need for specific adaptations or particular programmes in specific settings. In contemporary ASD interventions the principles of naturalistic developmental behavioural approaches (NDBI) implies the need to understand the environment and customs in a specific community setting, in order to make the required environmental arrangement and use suitable behaviour principles to address and improve outcomes (Schreibman et al., 2015; Daley, Singhal and Krishnamurthy, 2013; Guler et al., 2017).

Economic status and contextual factors not only influences aspects of the treatment process such as availability and access to resources, but also the degree to which a disability impacts functioning and whether individuals have the need for a certain problem to be addressed (Daley, 2002). Even if individuals in HIC and LMIC experience the same functional impact we cannot assume that they attach the same value to these components, or that their daily functioning are being impacted in similar ways. Hall and Hill (1996) highlighted to the important impact of environmental factors on functioning when they said that the interaction of several factors such as the health condition, family attitudes, societal attitudes, the physical environment and financial resources determines the extent to which a condition is perceived as a handicap. For example, individuals living with a physical disability in a society where public transport and public spaces are adapted for people with disabilities (e.g. wheelchair users) and where laws promote equal opportunity in employment, will experience the impact of their disability differently to people living in a society that does not provide the above, even though they may be experiencing the exact same physical symptoms.

Hall and Hills's statement therefore raises the empirical question whether ASD affects individuals in a LMIC to the same extent and in similar functional areas as it does in a HIC.

Bronfenbrenner's ecological model (Bronfenbrenner, 1994) provides a theoretical framework through which to view the impact of the environment on an individual's experience of disability. The model can be visualised as a series of concentric circles with the individual at the center. The concentric circles represent different levels of the environment. The levels are described from proximal to distal (see figure 1.2 below).

The microsystem level is the closest to the individual and has the most direct impact on his/her development. Factors on microsystem level include relationships (for example with parents, teachers, friends), the immediate, physical environment in which the individual lives and grows (for example the home or school), and the objects or physical resources in the immediate environment (for example food, furniture and toys).

The mesosystem refers to how factors within the microsystem interact with each other. Examples are parent-teacher relationships, parents' relationships with each other and parental interaction with the immediate environment.

The exosystem involves resources or infrastructure that is not in the immediate environment of the individual, but in the wider environment such as the city or region in which the he/she lives. Examples include the availability of clinics, hospitals, special schools, as well as the ability of the services offered to meet the needs of individuals with a disability.

The macrosystem level is the most distal level and involves the culture in which the individual lives. This includes beliefs, assumptions, stigma, religion, the economy and government.

The chronosystem refers to time and how things change over time.

Within this model the levels are interconnected and influence each other. For instance, factors at the macrosystem level, such as the economy, can influence factors on the microsystem level, such as the home environment in which someone grows up.

The significant differences in potential environmental factors between individuals and families who live with ASD in HIC and LMIC raises the question about the similarities or differences in the functional consequences of ASD in potentially very differently-resourced environments. It is possible to imagine that health and educational systems and services may be more available and better resourced in HIC than LMIC. This may directly impact the child with ASD's microsystem as it can result in the presence of trained teachers and/or professionals in the child's immediate environment. The presence of such skilled individuals can impact the child with ASD's developmental and functional trajectory. Another example is a child growing up in a culture (macrosystem) where ASD is highly stigmatized, as is often,

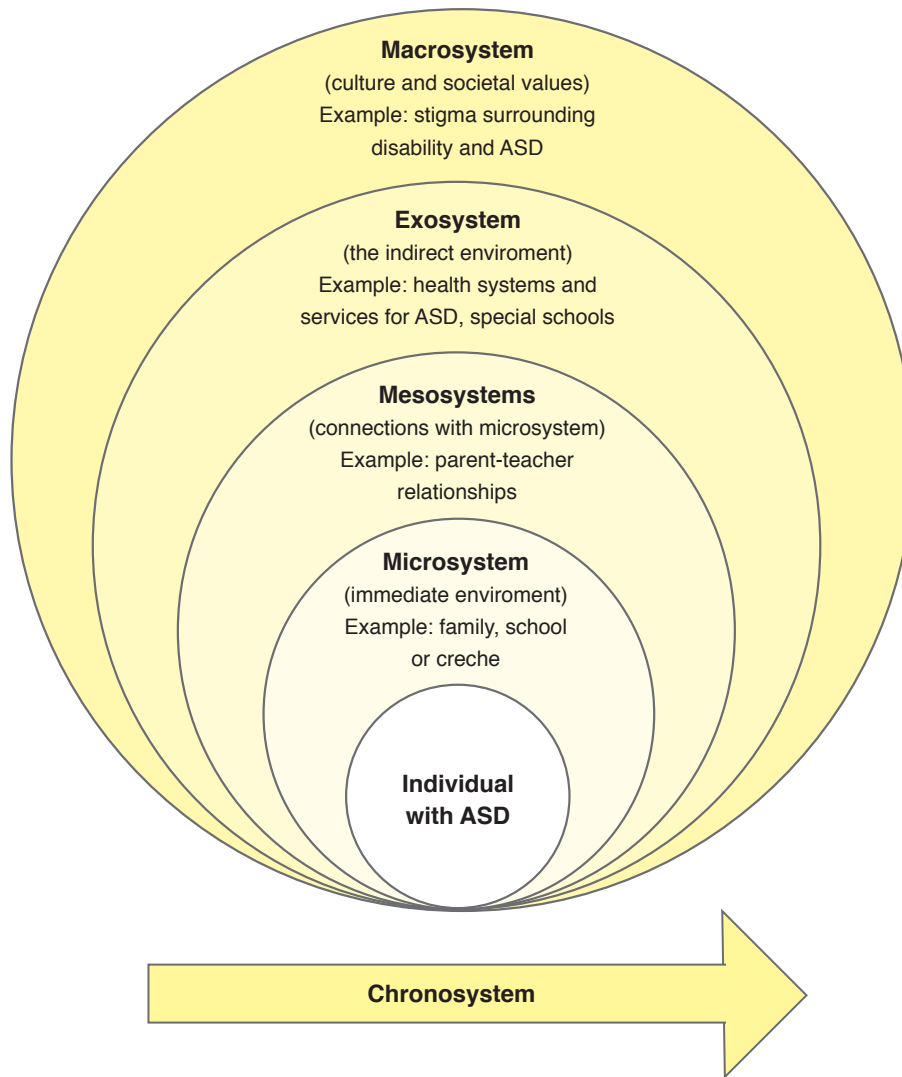


Figure 1.2 The impact of the environment on an individual's experience of disability adapted from Bronfenbrenner's ecological model (1994).

but not always seen in LMIC. Societal attitudes towards ASD can result in the child having fewer opportunities than in a setting where stigma is less of a problem, which can impact the child's exosystem and immediate environment (microsystem).

To investigate the difference in perceptions about functioning in LMIC and HIC, in ASD for the purpose of this study, we will use the Berry et al. (2002) universal viewpoint which assumes that basic underlying characteristics (and causes) are similar to all individuals with a particular condition, but that these characteristics may be subject to culture in its development and presentation (Daley, 2002).

In light of this universal viewpoint the limited literature regarding ASD in LMIC has suggested some similarities with and differences from HIC literature. Similarities that have been reported include higher prevalence amongst males, associated genetic disorders such as Tuberous Sclerosis Complex, Rett syndrome and Fragile X, as well as associated co-morbidities such as intellectual disability and epilepsy (Newton and Chugani, 2013). A UK-developed parent intervention program that had been culturally adapted and implemented in Pakistan and India showed similar treatment effects in India/Pakistan as it did in the UK (Rahman et al., 2016). Rahman argued that this suggest some universality as it points to the same developmental processes in ASD within the very different cultural contexts of South-East Asia and the UK. Differences between high socio-economic and low socio-economic communities relating to ASD include, but are not limited to, later diagnosis, inadequate referral from primary health care workers, poor access and availability of diagnostic and intervention services and lack of trained health care workers (Malcolm-Smith et al., 2013; de Vries, 2016, Franz et al., 2017) in LMIC. Overall, the comparative literature between HIC and LMIC has, however, been very limited.

1.5 Parental perceptions of functioning

According to Bronfenbrenner's model parents and caregivers form part of the microsystem level and are likely to have the most direct impact on an individual's development. Parents or caregivers are arguably the most important people in the life of a young child with ASD as they directly influence the social setting, support, relationships, stimulation and services that are accessed in the crucial first few years, as well as throughout childhood and teenage years. Parents are most likely to notice the first signs of ASD and have the responsibility to seek assessment and intervention for their child. In some countries, especially low-income countries with fewer resources, the burden of care falls almost entirely on parents (Qian, Chle and Bogenschutz, 2012; Minhas et al., 2015). The functional impact of ASD is most often the first warning signs to parents, and therefore the motivating factor in starting the diagnostic and intervention process. For example, functional delays in speech and language development, or in communication, and challenging behaviours are often the functional markers that will trigger parents to seek access to assessment and treatment. (Coonrod and Stone, 2004; Baker-

Ericzén, Brookman-Frazee and Stahmer, 2005; Guinchat et al., 2012; Azad and Mandell, 2016). The functional ability/disability of the child with ASD are also key determinants of parental stress and quality of life (Coonrod and Stone, 2004; Tomanik, Harris and Hawkins, 2004; Baker-Ericzén, Brookman-Frazee and Stahmer, 2005; Estes et al., 2009; Azad, Blacher and Marcoulides, 2013; Chiang and Wineman, 2014; Ikeda, Hinckson and Krageloh, 2014).

Given the above, there is therefore a strong rationale to focus on parental perceptions of ability and disability in order to examine to what extent ASD may have universal versus differential functional impact in differing socio-economic and cultural settings.

The majority of evidence and research to describe and define 'functional' impairment has typically come from professionals who work with children and young people. In a systematic review on ASD and functioning as part of the ICF core set development process for ASD, de Schipper and colleagues (de Schipper et al., 2015) identified only 17 out of a total of 71 studies where information was obtained from either parents or peers. All the identified studies in the de Schipper review came from HIC. No global literature review summarizing parental perceptions on functioning has been identified.

1.6 International Classification of Functioning (ICF)

The World Health Organization (WHO) International Classification of Diseases (ICD) is used in diagnostic clinical practice around the world (World Health Organization, 1992). To complement this categorical diagnostic system of the ICD, the WHO has developed a functional classification system, known as the International Classification of Functioning, Disability and Health (ICF). The aim of the ICF is to describe functioning and disability in the context of environmental factors and ICD diagnosis, in order to give a comprehensive picture of how a specific diagnosis impacts an individual's life. The ICF was extended to include a child and young people specific set, known as the ICF-CY (World Health Organization, 2007).

The ICF uses a biopsychosocial framework as mentioned above (1.3 Functioning in ASD). This framework includes five core components of body functions, body structures, activities and participation, environmental factors,

and personal factors. These factors interact with each other to influence functioning and are classified and described in the ICF manual. Each of these core components are described in four different levels of depth. As demonstrated by figure 1.3 the first level consists of chapters which gives an overview of the area of functioning. Chapters are then classified into three hierarchical categories or levels which describes the area of functioning in increasing detail.

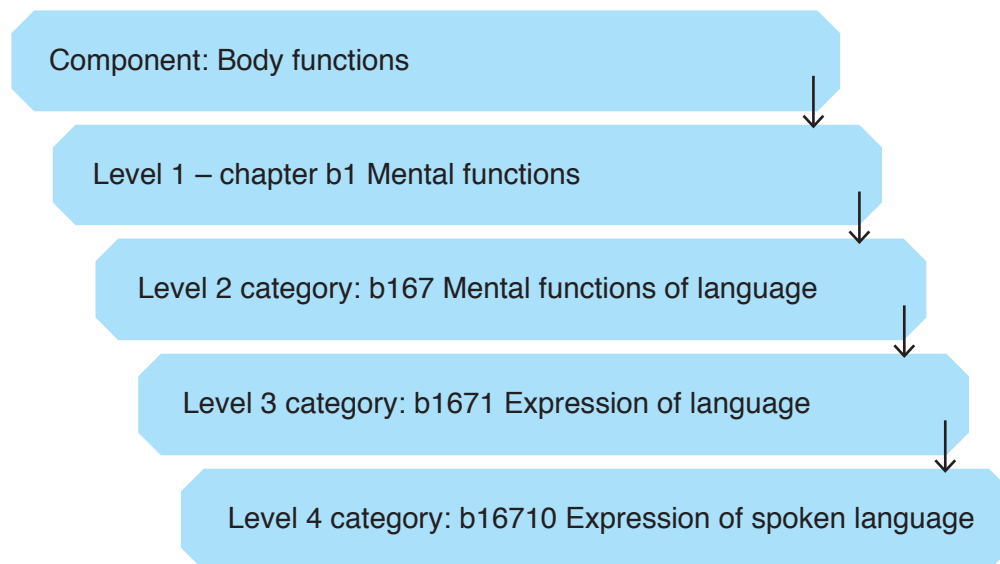

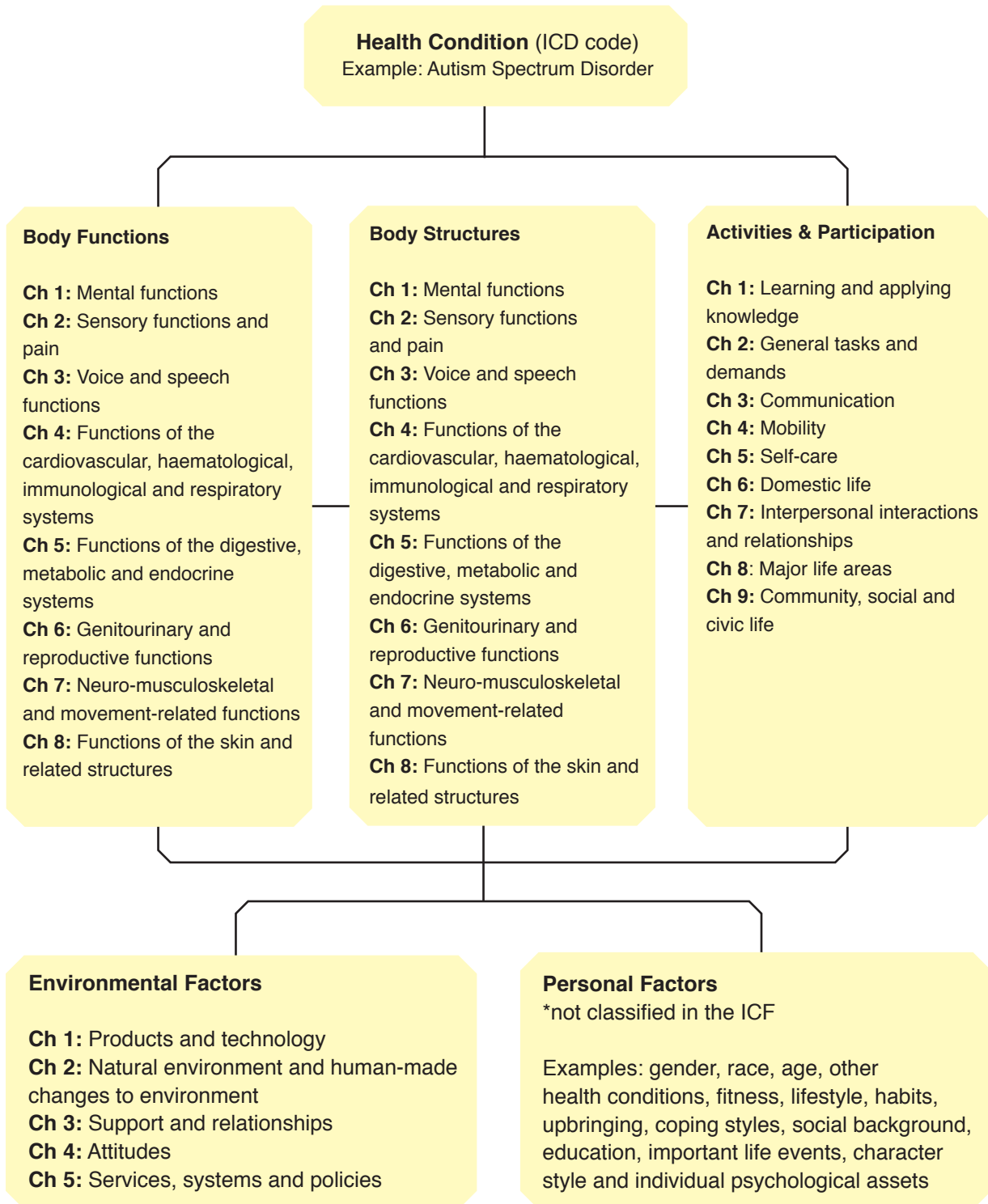


Figure 1.3 A schematic representation of the ICF process of functioning and disability showing the increase of detail in each level from the most general (component level) to most detailed (level 4 category).

The ICF defines body structures as the anatomical parts of the body such as organs, limbs and their components. Body functions are defined as the physiological functions of body systems and includes psychological functions. Activities & participation are grouped together as one ICF component with nine (9) chapters (see Figure 1.4). Activity can be described as the execution of a task or action by an individual, while participation is the involvement in a life situation. Activity limitations are difficulties an individual may have in executing activities, while participation restrictions are problems an individual may experience in involvement in life situations (World Health Organization, 2007). Environmental factors can be defined as ‘the physical, social and attitudinal environment in which people live and conduct their lives’. These factors are external to individuals and can have a positive or negative influence on the individual’s performance as a member of society, on the individual’s capacity to execute actions or tasks, or on  individual’s body function or structure (World Health Organization, 2007). Personal Factors are not classified in the ICF because of the large social and cultural differences associated with them.



They are difficult to clearly define, but can best be described as features that are part of someone’s background and not the health condition. These factors play an important role in a person’s overall functioning and can influence and interact with disability in many ways. Figure 1.4 shows the ICF components and the chapters classified under them.



Ch = chapter

Figure 1.4 The key components of the ICF and its chapters.

In recent years there have been efforts to develop ICF 'core sets' for specific conditions, including ASD. Core sets represent shorter lists of ICF categories of specific relevance to the specific health condition. The aims of core sets are to provide useful standards for research and clinical practice as well as to create a common language for functional ability and disability in particular conditions.

The process for developing these core sets follows a standardized procedure developed by the WHO ICF team. This standardized approach consists of four preparatory studies, including 1) a systematic review, 2) an expert survey, 3) a patient and caregiver qualitative study, and 4) a clinical cross-sectional study. Once all four preparatory studies have been completed, the final ICF categories to be included in the ICF core sets are confirmed at an ICF core set consensus conference, facilitated by the ICF research branch.

Over the last number of years, core sets have been in development for ASD (Bölte et al., 2014). The process followed the standard WHO procedure and included a systematic review (de Schipper et al., 2015), an expert survey (de Schipper et al., 2016), focus groups or semi-structured interviews from all WHO regions as part of the patient and caregiver qualitative study (Mahdi et al., 2017), and a clinical cross-sectional study (Mahdi et al., 2018). The final consensus conference to generate core sets took place in September 2016 in Stockholm under the direction of the project lead, Professor Sven Bölte from the Karolinska Institute.

As part of phase 3 (patient and caregiver qualitative study) focus groups or in-depth interviews with individuals living with ASD, family members and teachers were conducted in five countries around the world. These five countries included Canada, India, Saudi Arabia, South Africa and Sweden. The purpose of the focus groups was to explore and understand the perspective of individuals with ASD and their family members, teachers, and/or spouses on functioning and health. A set of questions covering the components of the biopsychosocial model were used to guide the discussion in semi-structured individual interviews as well as focus groups of 4–8 people under supervision of a moderator. Data collected during focus groups and semi-structure interviews were coded according to ICF coding principals (Cieza et al., 2002; Cieza et al., 2005; Mahdi et al., 2017).

The study by Mahdi and colleagues (2017) identified 45 categories relating to activities & participation, 33 to body functions, 29 to environmental factors and 3 relating to body structures. The most identified category relating to activities &

participation was 'carrying out daily routine'. 'Higher level cognitive functions' was the most identified in the body functions component and 'immediate family' the most identified in environmental factors. Comments on the positive aspects of ASD included honesty, attention to detail and memory skills (Mahdi et al., 2017).

The above results were based on pooled data from all the study sites without consideration of potential differences across different parts of the world. It also didn't differentiate between perspectives from immediate family members, caregivers and individuals with ASD. Furthermore, these results did not attempt to provide any qualitative information on what was said about the identified categories, thus limiting our understanding of how these aspects of functioning impacts daily functioning.

1.7 Purpose of the Study

ASD is heterogeneous in nature and functional outcomes can be very different in different individuals. We know that functioning is strongly correlated to context which may have a strong modifying role on ability and disability. Here we were particularly interested in the functional impact of ASD on children as judged by immediate family members. The ICF is a widely-used instrument to measure functioning and recent efforts have been made to develop core sets for ASD. This process very appropriately had a deliberate step to include parent/caregiver perceptions of functioning (Mahdi et al., 2017). Data from a range of HIC and LMIC were included. However, data across these highly divergent contexts were pooled for the purpose of core set development. Given the crucial role of context on functioning, it is therefore unclear whether the items identified in this process were universally reported across HIC and LMIC, or whether there may have been uniquely different profiles of functional ability and disability associated with these different settings.

The purpose of this study was therefore to examine the impact of the context on functional ability and/or disability in children with ASD based on parent/caregiver perceptions of functioning by examining the existing global literature about ability and disability in ASD, and by deliberately comparing and contrasting two of the most divergent countries who participated in the ASD core set development project.

1.7.1 Study aims

Aim 1

To explore the current knowledge-base about parent/caregiver perceptions on the impact of ASD on functioning around the globe using the ICF framework.

Aim 2

To explore the similarities and differences between common functional ICF themes relating to ASD in two contextually contrasting settings.

Aim 2A

To identify and compare the frequency of the most commonly reported functional ICF items identified in the core set preparatory study between a HIC and LMIC.

Aim 2B

To examine and compare the content of the most commonly reported items identified. That is, to examine whether a particular functional skill was positively or negatively influenced in the HIC and/or LMIC under investigation.

1.7.2 Hypotheses

Aim 1

1. We predicted that:

- a) more literature will be available from HIC than LMIC, and
- b) that literature from LMIC would be more concerned with environmental factors, in contrast to literature from HIC which would cover environmental factors as well as activities and participation, body functions and body structures.

Aim 2

2. We predicted that:

- a) body structures and body functions (ICF categories from chapters 1 and 2) would show similar frequency of reporting by parent/caregivers in LMIC and HIC settings given that body structures and functions describe the absolute or universal elements of ASD.
- b) environmental factors (ICF categories from chapter 4) would be more frequently reported by parents/caregivers in relation to their child's functional impairment in LMIC settings where resources may be less, than in HIC settings.
- c) environmental factors would be predominantly mentioned as a facilitator to functioning in children with ASD in HIC and a barrier in LMIC.

1.8 Overall study design

The study will be divided into two phases to meet the two main aims of the project.

Phase 1 (Aim 1) – A scoping review of existing global peer-reviewed literature on parental perceptions of functioning.

Phase 2 (Aim 2A) - A descriptive secondary quantitative frequency analysis of data from the ICF Core Sets for ASD qualitative study (Mahdi et al., 2017) to identify, compare and rank high frequency items in a HIC (Sweden as model country) and a LMIC (South Africa as model country).

Phase 2 (Aim 2B) - An in-depth qualitative content analysis of items identified in the frequency analysis to determine whether functional themes identified in South African and Swedish data were referenced in a facilitatory (positive) way or as barriers (negative) to functioning.

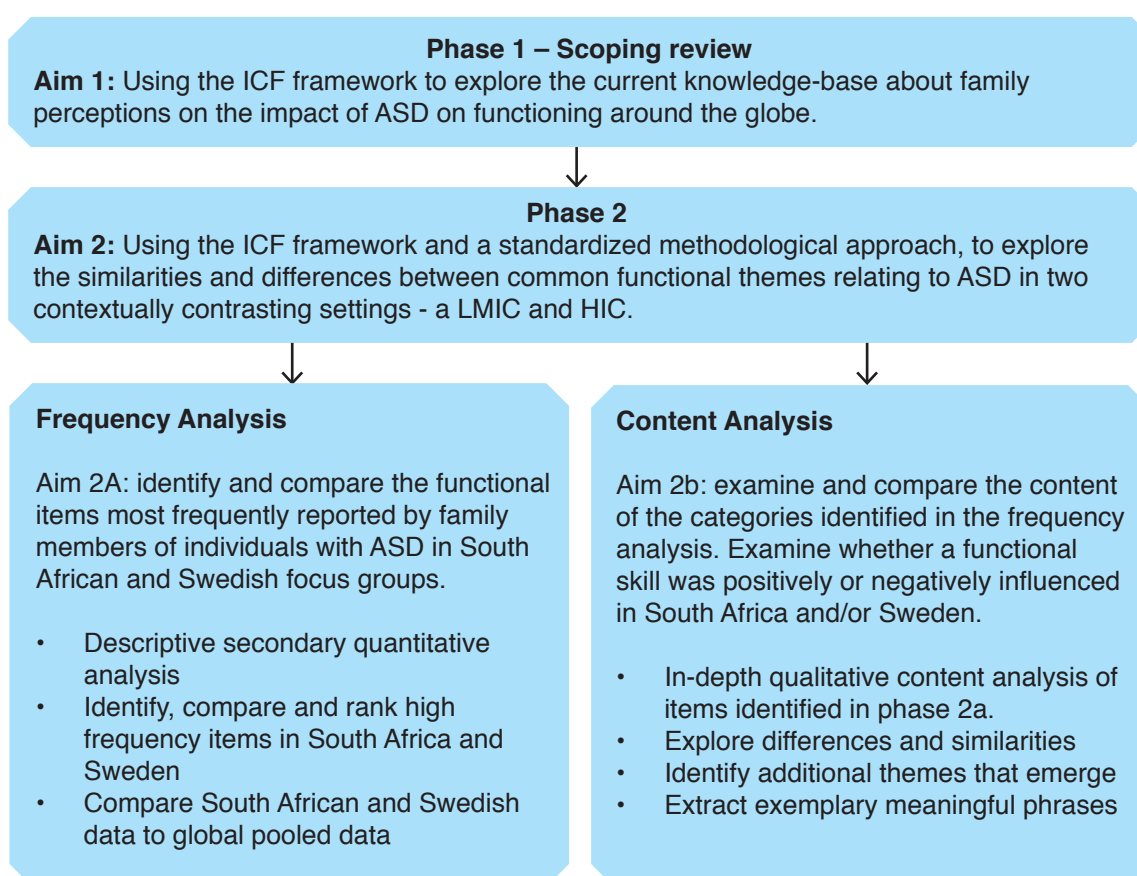


Figure 1.5: Schematic overview of the study over both phases

CHAPTER 2

Parental perceptions of functioning in their children with autism spectrum disorder (ASD): a global scoping review

2.1 Background

Autism spectrum disorder (ASD) is recognized by the World Health Organization (WHO) as a global public health concern (World Health Organization, 2013) with a global prevalence rate in excess of 1% (Elsabbagh et al., 2012; Baxter et al., 2015; Christensen et al., 2016). Importantly, approximately 90% of individuals with ASD live in low/middle-income countries (LMIC) (de Vries, 2016; Kieling et al., 2011; Franz et al., 2017). Although the clinical characteristics of ASD present the same in individuals who live in high-income countries (HIC) and LMIC (Newton and Chugani, 2013; Abubakar et al., 2016; de Vries, 2016), the significant contextual differences between HIC and LMIC may result in very different functional consequences (Daley, 2002).

Given the pivotal role of parents in identifying and managing the functional impairments in their children with ASD, the fact that functional markers are the typical drivers for help-seeking behavior, and the fact that functional ability/disability are key determinants of parental stress and quality of life (Coonrod and Stone, 2004; Tomanik, Harris and Hawkins, 2004; Baker-Ericzén, Brookman-Frazee and Stahmer, 2005; Estes et al., 2009; Azad, Blacher and Marcoulides, 2013; Chiang and Wineman 2014; Ikeda, Hinckson and Krageloh, 2014), we wanted to investigate parents' views on the functional challenges and/or strengths of their children with ASD. This knowledge could inform service planning, development of parent support and other ASD interventions, and could identify specific themes for future research. No previous reviews have summarized global data in this regard.

The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) and its Children and Youth version (ICF-CY) (World Health Organization,

2007) uses a biopsychosocial framework to describe functioning through the interaction between the clinical characteristics of a health condition, such as ASD, and contextual factors. The ICF model includes five interactive components, namely body structures (anatomical parts of the body), body functions (physiological functions of the body, including psychological functions), activities & participation (execution of tasks and/or involvement in life situations), environmental factors (external physical or social factors and attitudes), and personal factors (background and cultural factors) (World Health Organization 2001, 2007).

The ICF manual classifies and describes these core components at four hierarchical levels. The first level, or 'chapter' level, gives an overview of the component of functioning and each level thereafter describes it in increasing detail. Personal factors are not classified in the ICF as a result of the challenges associated with classifying social and cultural differences (World Health Organization 2001, 2007).

We therefore set out to perform a scoping review of parental perceptions of functional ability/disability in ASD using the ICF framework. Our objectives were a) to identify and collate global results to provide a broad description of the global landscape of parental perception of functioning research, and b) to summarize these using the WHO ICF framework. Given the important role that context plays in influencing functioning, we were specifically interested in exploring and comparing parental perceptions in HIC and LMIC countries in this regard.

We predicted that more literature would be available from HIC than LMIC, and that literature from LMIC would be more concerned with environmental factors, whereas literature from HIC would cover both environmental factors as well as activities and participation, body functions and body structures.

2.2 Methods

2.2.1 Study design

The methodological framework for conducting scoping reviews as set out by Arksey and O'Malley (Arksey and O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010) was followed. This included identifying the research question, searching for relevant studies, selecting studies, charting and summarizing the data and reporting results. As stated above, the research question for this review was identified in advance.

2.2.2 Search strategy

A comprehensive search was conducted of PsychInfo, PubMed, Scopus, CINAHL (Cumulative Index to Nursing & Allied Health Literature) and Africa-wide through the Ebscohost interface. Search terms were truncated when appropriate to maximize recall. Inclusion criteria comprised the following: original studies published in a peer-reviewed English-language journal, studies published between 1990 and June 2016, study participants included parents of individuals with ASD, the topic of study could clearly be related to an area of functioning as defined and categorized by the biopsychosocial model used in the ICF. Opinion pieces, commentaries, editorials and non-data containing letters were excluded. Two researchers (the author and a study collaborator) searched the same free text terms with Boolean operators on the same day.

Free text terms related to parent perception on functioning in ASD included "autism spectrum disorder", "ASD", "autism", "autistic disorder", "pervasive developmental disorder", "aspergers syndrome", "asperger syndrome", "asperger's syndrome" and a combination of the following in the Title, Abstract or Keyword search fields: parent* perceptions, parent* perspectives, parent* knowledge, parent* attitudes, parent* beliefs, parent* understanding ability, disability, function, functioning. All searches included at least one identifier for ASD (e.g. "autism spectrum disorder", "ASD", "autism) linked to at least one identifier for parent perceptions (e.g. parent* perceptions, parent* perspectives, parent* knowledge).

A systematic selection process was used to arrive at the final article set. The two researchers (the author and study collaborator) independently recorded the total number of articles identified in the search. All duplicates and records that met the exclusion criteria were removed. The final number included

for review was compared, after which titles and abstracts were screened. Potentially relevant articles were assessed for eligibility in full and consensus was reached as to which articles to include in the review. Where consensus could not be reached, the principal investigator of the study was consulted. The number of records screened, the number included, the number excluded as well as reasons for inclusion and exclusion was recorded (see figure 2.1). Researchers could reach consensus during most stages of the selection process and the principal investigator was consulted only once to assist in decision-making regarding inclusion or exclusion of articles.

We used World Bank income groupings to differentiate between HIC and LMIC. The World Bank group member states into low-and middle income countries (LMIC) and high-income countries (HIC) (The World Bank, 2017a). Middle-income countries are further sub-divided into lower-middle income countries and upper-middle income countries by the World Bank (World Bank, 2017a).

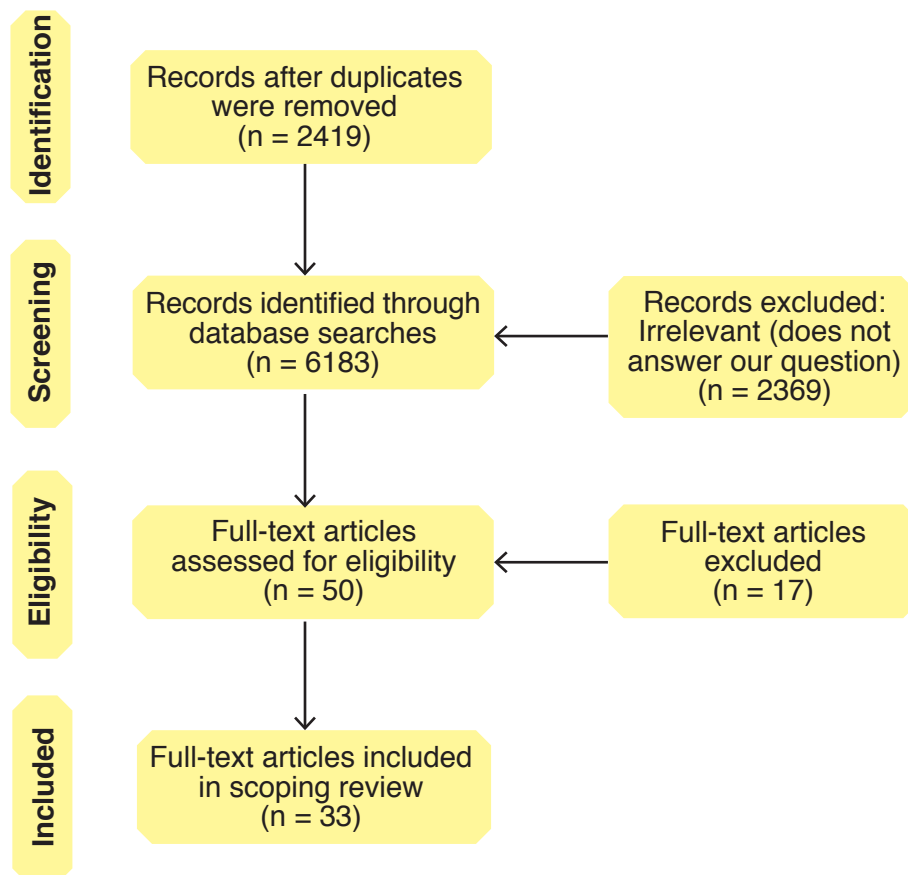


Figure 2.1 PRISMA flow diagram of studies screened, included and excluded in the scoping review.

2.2.3 Data analysis

Full-text of all included articles were accessed and summarized in the summary tables to describe their basic characteristics. Summary tables included first author, year, country, study design, measures, study population and sample size, purpose/aims of study, measures and key findings relating to scoping review question (see table 2.1).

Given that we wanted to use a well-established theoretical model of functioning and had selected the ICF biopsychosocial model, we next proceeded to link key findings to ICF first or second-level categories (see table 2.1). Key findings were linked by the author using the same linking process used in the WHO-defined Core Sets development procedure, as described in the systematic literature review (de Schipper et al., 2015) and expert survey (de Schipper et al., 2016) that formed part of the ASD ICF core set preparatory studies. The first step of the linking process was to identify meaningful concepts describing aspects of ability and/or disability from key findings. Next these meaningful concepts were linked to corresponding ICF first or second-level categories. Where concepts were linked to third- or fourth level ICF categories only the second level category was reported (de Schipper et al., 2015).

In instances where it was unclear which ICF category described a meaningful phrase best, a combination of second-level categories in the same chapter was identified and clustered together. Since several meaningful phrases could be identified from key findings it was possible for one article to be categorized under more than one chapter and/or ICF first or second-level category.

2.3 Results

2.3.1 Descriptive findings

The electronic search resulted in 2419 records (see PRISMA flowdiagram, figure 2.1). After removal of duplicates and application of inclusion/exclusion criteria 33 articles were included in the scoping review. Given that this was a scoping review, no articles were excluded based on quality or bias criteria (Arksey and O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010). The general summary of all identified studies is shown in table 2.1. The ICF categories linked to studies are shown in table 2.2. Figure 2.2 shows a graphic representation of the findings superimposed on the ICF conceptual framework.

Table 2.1 Scoping review summary table. Low/Middle-income countries are indicated in grey.

First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Abu-Hamour, B 2013 Jordan	Qualitative descriptive analysis	Survey	148 parents of children with ASD	Explore the attitudes of parents towards inclusion in public schools. Examine parent perceptions of the most important prerequisite child-based skills for successful inclusion.	Parents' attitudes towards inclusion correlated with parental education levels and high-or low-function ASD. Parents mentioned independent skills, playing skills, behavioural skills, imitation skills, routine skills, social skills, paying attention skills, language skills, and pre-academic and academic skills as important for inclusion.	d5 self-care d7 interpersonal interactions and relationships d250 managing one's own behavior d130 copying – basic learning d230 carrying out daily routine d7 social interactions and relationships) b122 global psychosocial functions d330 – d349 Communication – producing
Adamson, A 2006 Scotland, UK	Quantitative cross-sectional	Short sensory Profile (completed by parents/ caregivers). Gilliam Autism Rating Scale (completed by parents/ caregivers). Clinical information from paediatric community child health medical notes.	44 children with ASD	To determine whether sensory modulation was disturbed in children affected by ASD. To determine whether there were any features in the child's clinical presentation that related to degrees of disturbance in sensory modulation.	Sensory reactivity was outside normal limits in over 70% of the children. The highest percentage of sensitivities occurring in the auditory filtering and the under-responsiveness and seeking sensation domains.	b1560 auditory perception b230 – b249 hearing and vestibular functions (<i>there is no clear category in the ICF for auditory sensitivity related to sensory processing</i>).
Azad, G 2016 USA	Mixed qualitative and quantitative	Individual interviews with teachers and parents Dyad observations (observing parents and teachers)	39 parent-teacher dyads	To examine parents and teachers concerns for children with autism.	Primary concerns for parents were deficits in social interaction, problem behaviour, and academics. Parents and teachers were concerned about communication and self-help. Parents' least common concern was restricted, repetitive, and stereotyped behaviors.	d7 social interactions and relationships b122 global psychosocial functions b125 dispositions and intra-personal functions d250 managing one's own behavior d810 – d839 education d3 communication d5 self-care b147 psychomotor functions b160 thought functions
Bal, A 2013 USA	Qualitative	In-depth semi-structured interviews	Parents of 3 children (3 sets of parents)	To examine parents' perspectives regarding social strengths.	Three social interactional strengths were identified and are discussed: Empathy Sensing fairness Story-telling	Personal factors – strengths

First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Barnhill, G 2013 USA	Quantitative	BASC Teacher Rating Scale (TRS). The Behavior Assessment System for Children (BASC).	20 children/ adolescents with Asperger Syndrome and their parents and teachers.	To identify and examine both problem and adaptive behaviours in children and adolescents with Asperger Syndrome as perceived by children, their parents and their teachers.	Parents were concerned about their children's behaviour and social skills. Parents reported significant deficits in socially related areas (of children). Aggression, Depression, Attention Problems, Withdrawal, Children's Adaptability, Leadership, and Social Skills subtest scales were areas of difficulty.	b125 adaptability d720 complex interpersonal interactions b140 attention functions d720 complex interpersonal interactions b1 mental functions b152 emotional functions b140 attention functions d160 focusing attention d161 directing attention d7 interpersonal interactions and relationships b126 temperament and personality functions Personal factors – associated health conditions
Brookman-Frazee, L 2012 USA	Qualitative	Semi-structured interviews	23 parents of children with ASD	To examine parent perspectives on: clinical histories of children with ASD involved in CMH clinics, experiences accessing services and the impact of services on the child and parent functioning.	Describes parents' views on diagnostic history and process, co-occurring problems, positive and negative impacts of child characteristics on family, service access, child characteristics (behaviour problems), role of education system, service navigation issues, lack of clinician ASD training and specialized ASD services.	e585 education and training services, systems and policies e580 health services, systems and policies e575 general social support services, systems and policies e355 health professionals Personal factors – strengths, associated health conditions
Brown, H 2010 Canada	Quantitative - descriptive statistics. Cross-sectional	The Family Needs Questionnaire Scales of Independent Behaviour-Revised (Short Form) Impact on Family Scale Additional questions developed by the research team (family characteristics)	97 families	The objective was to explore the association between children's functioning and parents' perceived unmet needs.	Families of children with high functional independence had lower unmet need than families of children with moderate functional independence. The relationship between functional independence and perceived unmet need appeared to change depending on the extent to which families perceived their child's disability to be a burden.	Activities and participation – unable to link to more specific ICF categories.
Cavalari, R N S 2012 USA	Quantitative	Online, anonymous survey. Modified version of the CSIQ (B-CSIQ) questionnaire, IBC questionnaire and the PDD Behaviour Inventory questionnaires	Phase I: 79 adult participants Phase II: 35 parents	To investigate potential patterns of injury based on parent report.	ASD symptom severity positively correlated with risk-taking behavior and frequency of injury, children with an ASD were rarely rated as high risks for injury by caregivers. Children with an ASD appears to have different patterns of risk-taking behaviors, injury, and subsequent risk.	d750 looking after one's health d571 looking after one's safety d330 – d349 communication – producing d310 – d329 communication – receiving

First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Coonrod, E 2004 USA	Qualitative	Interviews - open-ended as well as specific questions	44 parents (22 with autism, 22 with developmental delay)	To look at early concerns of parents of children with autism	The age of children when parents first became concerned and the specific nature of first concerns were similar for both groups, Most frequent concerns related to children's language development. Parents of children with autism reported more deficits in social and communicative behaviours than parents of development delay.	b167 mental functions of language b3 voice and speech functions d330 – d349 communication – producing d133 acquiring language d7 interpersonal interactions and relationships d330 speaking d335 producing nonverbal messages d331 pre-talking
Gilligan, P 2013 UK	Qualitative	Groups and individual interviews	16 parents	To develop sessions to include in a parent program for Muslim communities	Parents had a need for specific support from practitioners and religious leaders and from each other to deal with the challenges they face as a result both of hearing explanations for their children's behavior/ characteristics and from trying to ensure that they and their children meet religious requirements.	e460 societal attitudes e310 immediate family, e410 individual attitudes of immediate family members and/or e325 acquaintances, peers, colleagues, neighbours and community members. Personal factors – spiritual beliefs
Gona, J K 2016 Kenya	Qualitative	Interviews and focus group discussions	37 interviews and 8 focus group discussions	To establish what are the challenges faced by parents of children with autism on the Kenyan coast and what coping strategies these parents apply.	Parents reported challenges including stigma, lack of appropriate treatment, financial and caring burdens regardless of their religious and cultural backgrounds. Parents used diet management, respite care, beliefs in supernatural powers, prayers and spiritual healing to manage.	e460 societal attitudes e580 health services, systems and policies e355 health professionals d570 looking after one's health e585 education and training services, systems and policies Personal factors – spiritual beliefs and factors relating to parents
Goodman, S 2012 USA	Qualitative	Maternal Perception of Child Attachment (MPCA) Postnatal Attachment Questionnaire (PAQ) Parenting Stress Index/Short Form (PSI/SF) Childhood Autism Rating Scale-Parent Version (CARS-P) Parenting Sense of Competence Scale (PSOC) Paulhus Deception Scales (PDS)	106 parents (76 mothers; 30 fathers)	Examined the relationship between parents' perceptions of their child's attachment to them and their own affective attachment to their child. Also looks at the relationship of the above to parenting stress, parents' perceptions of their child's functional impairment, and parenting sense of competence.	Results suggest that parents of older children tend to perceive their children as having greater functional impairment. Parents' affective attachment to their child was more consistently related to other aspects of their parenting experiences than were their perceptions of their child's attachment to them.	d7 interpersonal interactions and relationships

First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Guinchat, V 2012 France	Qualitative and quantitative	Questionnaires (designed for the study)	459 parents of children with ASD completed the questionnaires, from all over France between 2005 and 2007	To address the warning signs and developmental abnormalities perceived by parents of children with ASD; assess variables associated with a diagnostic delay (i.e., patterns of concern, mother vs. father, child's gender); and practical implications for diagnosis.	Parent's responses were categorised into 10 general (G) domains of symptoms: abnormal socio-emotional development; delayed language development; autistic-type behaviors (i.e., stereotypes); behavior difficulty not specific to autism; abnormalities concerning major physiological functions (feeding problems, sleeping problems, incontinency); anomalies in motor milestones; perceptive abnormalities; medical disorders (e.g., seizures); loss of previously acquired skills; and other concerns.	d7 interpersonal interactions and relationships d3 communication d330 – d349 communication – producing b134 sleep functions d550 eating b250 taste functions b265 touch functions b620 Urination functions b525 defecation functions d530 toileting d250 managing one's own behavior b140 attention functions d160 focusing attention d161 directing attention
Heys, M 2016 Nepal	Qualitative	12 focus groups and 9 semi-structured interviews.	106 Parents of autistic and non-autistic children and education and health professionals	The purpose was to investigate the extent and nature of understanding of autism in parents of autistic and non-autistic children and among health and education professionals in Nepal.	Parents of typically developing children and professionals had little awareness of autism. They used some distinctive terms to describe children with autism from children with other developmental conditions.	e310 immediate family e410 individual attitudes of immediate family members e460 societal attitudes e355 health professionals e5 services, systems and policies Personal factors – nature of children
Ho, B P V 2012 Australia, Canada, New Zealand, South Africa, UK, and USA	Quantitative	Information from a national internet forum for parents of children with ASD	Information about the angry episodes of 121 children with ASD as described by 120 parents	To explore parent perceptions of the anger exhibited by children with ASD.	Children with ASD were angry frequently with aggressive behaviours, their anger was target and context specific, unable to control their behaviours, some were apologetic afterward. These behaviours impacted on the whole family, their parents, their siblings and the children with ASD.	d250 managing one's own behavior d7 interpersonal interactions and relationships d230 carrying out daily routine
Hwang, Y 2013 Singapore	Mixed qualitative and quantitative.	The Parent Questionnaire on Mind and Autism Spectrum Disorder (PQMA) and Teacher Questionnaire on Mind and Autism Spectrum Disorder (TQMA)	133 Singaporean parents and teachers	To explore views of parents and teachers concerning the inner experience of learners with ASD and cognitive difficulties.	Learners show a greater awareness of their own mental states compared to their ability to understand these same mental states in others. According to parents and teachers learners with ASD (and cognitive difficulties) experience happiness, anger, fear, sadness. Happiness, anger and sadness are perceived as being understood in others. They have difficulty understanding thinking, fear, desire and loneliness in others.	d7 interpersonal interactions and relationships


First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Kissel, S 2014 USA	Quantitative	GARS-2, Parenting Stress Index–Short Form (PSI-SF), Family Assessment Measure–Third Edition (FAM-III), and Family Support Scale (FSS)	64 parents	To examine differences in parental stress, family functioning, and social supports in light of the parents' perceptions of the severity of their child's autistic behaviors.	Parents of children with more severe autistic behaviors, parents of children with less severe autistic behaviors, and parents of children without disabilities have similar ratings of general family functioning and perceived helpfulness of social support.	e310 immediate family
Kite, D 2011 Australia	Qualitative	Focus group discussions	51 participants consisting of health and education professionals, parents of children with Asperger's, and community members	To explore the perceptions of Asperger's disorder among patients, families and professionals.	The following themes were identified: aetiology uncertainty, challenging behaviour, barriers in service provision, terminology confusion and stigma.	e310 immediate family d250 Managing one's own behaviour e580 Health services, systems and policies e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members e460 Societal attitudes
Knott, F 2006 Scotland, UK	Quantitative cross-sectional study	Spence Social Skills Questionnaire; Social Competence with Peers Questionnaire; Individual Parent Ratings: 'Three Things' to change	19 families consisting of both parents of and children with ASD	To explore and compare perceptions of social skills and competence between parents and children with ASD.	Children with ASD recognised their difficulties with social skills and social competence. Parents reported lower levels of social skill and social competence than their children with ASD did	d7 Interpersonal interactions and relationships),
Lee, L 2008 USA	Quantitative cross-sectional study	Secondary analysis of data from the National Survey on Children's Health	Parents of 483 children with ASD, 6319 children with ADHD, and 58953 unaffected controls, aged 3-17	To examine the quality of life and parental concerns in children with ASD.	Parents of children with ASD more frequently report that their children have diminished quality of life, have higher levels of concerns about their child's well-being than other groups. Children with ASD were less likely to attend religious services, more likely to miss school, and less likely to participate in organized activities. Parental concerns over learning difficulty, being bullied, stress-coping, and achievement were overwhelming in the ASD group.	d930 Religion and spirituality Education d810-d839) Chapter 3 Activities and participation e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members d7 interpersonal interactions and relationships d240 handling stress and other psychological demands
Miller-Gairy, S 2015 USA	Qualitative	Ethnographic case study, consisting of focus groups, participatory observations, and face-to-face interviews.	8 Somali mothers of 11 USA-born children with ASD, and 6 service providers.	To examine the role of culture and tradition in influencing perceptions and expectations in parents of children with ASD.	ASD is a new concept in the community. Lack of understanding of aetiology and origins of ASD. Inability to access resources. Misunderstandings between mothers and service providers. Being an immigrant adds to the burden of care due to lack of support.	e580 health services, systems and policies e355 health professionals OR e450 individual attitudes of health professionals). Personal factors – nature of children

First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Minhas, A 2015 Pakistan and India	Qualitative	Interviews Thematic analysis of literature data	15 Parents of children with ASD aged 7-16 in Pakistan; Narrative review of 5 studies exploring families' experiences with their children with ASD.	Explore the beliefs and practices related to care of children with ASD in Pakistan and India.	Mother usually the exclusive care-giver; little or no respite care available and high levels of caregiver stress. Delay in recognition of ASD; little awareness in the family; reliance on traditional healers. Difficult to access urban-centred care; lack of understanding in child-health professionals. Stigma is widely prevalent; lack of understanding in schools.	e310 immediate family e580 health services, systems and policies or e355 health professionals e460 societal attitudes
Moodie-Dyer, A 2014 USA	Qualitative	Semi-structured telephonic interviews Content analysis of data	19 parents/ caregivers of children with ASD	To explore parental and care-giver perceptions of and experiences with the ASD service delivery system.	Importance of individual coping strategies, such as social support, collaboration with service providers, advocacy and empowerment, determination and luck. Services and support have improved over time. Themes point to important enabling components at the individual and system level that promote access to care.	e580 health services, systems and policies and/or e355 health professionals e450 individual attitudes of health professionals
Ooi, Y P 2016 Singapore	Quantitative	Spence Children's Anxiety Scale-Children's; Spence Children's Anxiety Scale-Parent; Parenting Stress Index	70 Sets of children/ adolescents aged 9-16 with ASD and their parents	To examine the degree of agreement in parent and child-rated anxiety scores in children with ASD; Explore parent-child discrepancies in reported anxiety scores	Parent-child agreement ranged from low-moderate. Children rated themselves significantly higher on total anxiety scores compared to their parents. Discrepancies in some anxiety sub-scales were associated with the children's verbal cognitive ability and with levels of parenting stress.	b152 emotional functions
Qian, X 2012 China	Quantitative	Survey (regarding age at first concern; age at diagnosis; age at intervention; particularly salient symptoms)	146 Chinese parents of children with ASD	To understand the developmental markers associated with ASD in Chinese parents of children with ASD	Parental reports of number of symptoms were associated with earlier parental concern, but not with age at first diagnosis or intervention. Specific symptoms associated with earlier diagnosis reported. These included language acquisition, communicative issues. Age at first concern, but not first diagnosis, higher in Chinese than western populations. Symptoms of first concern were the same as western populations.	d133 acquiring language d3 communication d331 pre-talking b160 thought functions d7 interpersonal interactions and relationships e310 immediate family e460 societal attitudes

First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Quilendrin, M 2015 Philippines	Combination Qualitative and quantitative.	Interviews, focus group discussions and questionnaire specific to this study	55 Parents of Filipino children aged 2-6 with ASD	To describe parental perceptions of Autism and health-seeking behaviours for children with ASD	Improving awareness regarding ASD and the needs of children with ASD. Participants seem to be moving away from previous myths about ASD. Trend towards earlier recognition of symptoms and presentation to services.	e355 health professionals e560 media services, systems and policies e315 extended family e310 immediate family e330 people in positions of authority e360 other professionals e410 individual attitudes of immediate family members d3 communication d7 interpersonal interactions and relationships b160 thought functions
Rosenberg, L 2012 Israel	Quantitative	Environmental Restriction Questionnaire; Children Performance Skills Questionnaire (PSQ); Children Participation Questionnaire	Parents of 78 children with ASD	To assess whether parents of children with mild developmental disabilities perceived various environmental factors as barriers to their child's participation, and whether these factors have a unique contribution to the total explained variance of participation, beyond personal factors	Environmental factors have significant slight contribution to the child's independent participation beyond other predictors, such as personal factors. Recommended to include environmental restrictions in the child's assessment process, to facilitate effective interventions.	Chapter 4 - Environmental factors. Does not specify environmental factors sufficiently to link to specific ICF categories. Personal factors – social background
Salkas, K 2016 USA	Qualitative	Semi-structured interviews	34 Latina mothers of children with ASD	To explore how Latino parents of children with ASD incorporate spirituality into their conceptualisation of their child's disability.	Most mothers endorsed beliefs that their child with a disability was a message from God. Others attributed it to biomedical factors, while yet others were unsure. Some mothers reported that their larger cultural group attributed their child's diagnosis to spiritual causes or meaning, but that they rejected that conception.	Personal factors
Sasaki, Y 2015 Japan	Quantitative	Rating scale scores during different times of the day; Questionnaire-Children with Difficulties (QCD); ADHD-rating Scale (ADHD-RS); Tokyo Autistic Behaviour Scale (TABS); Oppositional Defiant Behaviour Inventory (ODBI)	Parents of 372 children aged 6-15 with PDD (pervasive developmental disorder) and 1510 unaffected control children aged 6-15	To Evaluate difficulties in daily functioning of children and adolescents with PDD.	QCD (Questionnaire: children with difficulties) scores significantly lower in PDD (pervasive developmental disorder) group. Children with PDD experienced greater difficulties in completing basic daily activities.	Chapter 3 Activities and participation This article does not mention specific tasks/activities, but instead looks at what time of the day the activity is performed. Unable to link to any ICF category.

First author, Year, Country	Study Design	Measures	Study Population and Sample Size	Purpose and/or Aims of Study	Key findings relating to research question	Linking of key findings to ICF categories
Sotgiu, I 2011 Italy and Cuba	Quantitative	2 x 2 case-control study using direct measurements on children and rating scales with mothers.	Mothers of 30 Italian children (15 with ASD, 15 controls) and 22 Cuban children (11 with ASD, 11 controls) aged 4-11	To analyse the relationship between ASD and the sociocultural and economic aspects of the context in which children with ASD live.	Significant differences between the two cultural groups in terms of the structure of the children's social network as well as parental attitudes toward their children. Mother-child attachment relationship and cognitive and emotional functioning of the participants were independent of culture.	e355 health professionals OR e360 Other professionals e310 immediate family Personal factors – social background
Twyman, K 2009 USA	Quantitative	Retrospective cross-sectional medical record review	Parents of 262 children with ASD	To investigate factors associated with age at diagnosis of ASD	Parental concerns about atypical behaviour and milestones were similar between the early- and late- diagnosis groups. Parents in the early diagnosis group noted social development concerns at an earlier age, suggesting that closer surveillance of this domain may facilitate earlier diagnosis and intervention.	d7 interpersonal interactions and relationships d3 communication
Wang, H 2013 USA	Qualitative	Semi-structured interviews	Parents of 6 Chinese or Taiwanese children with ASD living in the USA	To describe the experience of Mandarin-speaking immigrant parents raising a child with ASD in the USA	3 Themes emerged: 1) immigration and cultural accommodation; 2) impact of Autism and cognitive response; 3) outlook for the future.	Chapter 4 - Environmental factors. Does not specify environmental factors sufficiently to link to specific ICF categories.
Whitaker, P 2007 England, UK	Mixed qualitative and quantitative.	Parent questionnaires with rating scales and open-ended questions (level of parental satisfaction, and parents' priorities for service changes and improvements)	172 Parents of children with ASD attending mainstream schools	To explore and understand parental perceptions and experience of educational provision in mainstream settings for children and young people with ASD	Parental satisfaction was associated with the extent to which the school staff understood and empathized with their children's difficulties, and the perceived flexibility of the school's response to the children's needs, as well as the extent of reciprocal communication between the school and the parents. The school's role in promoting social development and social relationships emerged as a high priority concern for parents.	e565 education and training services, systems and policies e360 other professionals Personal factors – spiritual beliefs

List of abbreviations

ASD	Autism spectrum disorder The Behavior Assessment	CARS-P	Childhood Autism Rating Scale – Parent Version	FSS	Family Support Scale
BASC TRS	System for Children Teacher Rating Scale	PSOC	Parenting Sense of Competence Scale	QCD	Questionnaire: children with difficulties
BASC	The Behavior Assessment System for Children	PDS	Paulhus Deception Scales	PDD	Pervasive developmental disorder
ICF	International classification of functioning	PQMA	The Parent Questionnaire on Mind and Autism Spectrum Disorder	ADHD-RS	ADHD-rating Scale
CMH	Child mental health	TQMA	Teacher Questionnaire on Mind and Autism Spectrum Disorder	TABS	Tokyo Autistic Behaviour Scale
MPCA	Maternal Perception of Child Attachment	GARS-2	Gilliam Autism Rating Scale – Second edition	ODBI	Oppositional Defiant Behaviour Inventory
PAQ	Postnatal Attachment Questionnaire	USA	United States of America	UK	United Kingdom
PSI/SF	Parenting Stress Index/Short Form	PSI-SF	Parenting Stress Index–Short Form		Low/middle income country
		FAM-III	Family Assessment Measure – Third Edition		

Of the final 33 studies identified, most were conducted in HIC (n = 25/33, 76%) and the majority of studies from HIC came from the United States of America (USA) (n = 14/25, 56%). Three of the studies from HIC examined refugee or immigrant populations from LMIC living in HIC (Gilligan, 2013; Wang and Casillas, 2013; Miller-Gairy and Mofya, 2015). Only six studies from LMIC were identified (n = 6/33, 18%), of which four were from Asia - China, India & Pakistan, Nepal and Philippines (Qian, Chle and Bogenschutz, 2012; Minhas et al., 2015; Quilendrin et al., 2015; Heys et al., 2017), one from Africa - Kenya (Gona et al., 2016) and one from the Middle East - Jordan (Abu-Hamour and Muhaidat, 2014). One study compared perspectives from seven countries of which one was a LMIC (South Africa) (Ho, Stephenson and Carter, 2012), and another study compared perspectives from a LMIC (Cuba) and HIC country (Italy) (Sotgiu et al., 2011).

A total of 14 studies used qualitative methodology, 14 used quantitative, and five a combination of qualitative and quantitative methodology.

The main purpose/aims of the studies were highly varied. Some studies explored parents' general understanding, perceptions and challenges relating to their children with ASD (7 studies) (Goodman and Glenwick, 2012; Kite, Tyson and Gullifer, 2011; Minhas et al., 2015; Sasaki et al., 2015; Azad and Mandell, 2016; Gona et al., 2016; Heys et al., 2016), while others were concerned with broad aspects of functioning such as social skills, quality of life, daily functioning, strengths, sensory processing and impact on the family (7 studies) (Barnhill et al., 2000; Adamson, O'Hare and Graham, 2006; Knott, Dunlop and Mackay, 2006; Lee et al., 2008; Brown et al., 2011; Bal and Radke, 2013; Kissel and Nelson, 2014). A few studies explored perceptions related to emotional functions such as anger, anxiety and inner experiences (3 studies) (Ho, Stephenson and Carter, 2012; Hwang et al., 2015; Ooi et al., 2016), while several were concerned with warning signs and functional markers around diagnosis (6 studies) (Coonrod and Stone 2004; Twyman et al., 2009; Guinchat et al., 2012; Qian, Chle and Bogenschutz, 2012; Rosenberg et al., 2012; Quilendrin et al., 2015). Four studies specifically examined the impact of culture or different aspects related to culture such as spirituality, beliefs and practices (Gilligan, 2013; Wang and Casillas, 2013; Miller-Gairy and Mofya, 2015; Salkas et al., 2016) and six studies explored the impact of environmental factors such as health and education services and systems on functioning (Whitaker, 2007; Sotgiu et al., 2011; Brookman-Frazee, et al., 2012, Cavalari and Romanczyk, 2012; Abu-Hamour and Muhaidat, 2014; Moodie-Dyer et al., 2014).

Table 2.2 Scoping review ICF category table. Low/Middle-income countries are indicated in grey.

	ICF-CY components					Country classification		
	Body structures	Body functions	Activities & participation	Environmental factors	Personal factors	HIC	LMIC	Country
Abu-Hamour 2014			x				x	Jordan
Adamson 2006		x				x		UK
Azad 2016		x	x			x		USA
Bal 2013					x	x		USA
Barnhill 2000		x	x		x	x		USA
Brookman-Frazer 2012				x	x	x		USA
Brown 2011			x			x		Canada
Cavalari 2012			x			x		USA
Coonrod 2004		x	x			x		USA
Gilligan 2013				x	x	x		UK
Gona 2016				x	x		x	Kenya
Goodman 2012			x			x		USA
Guinchat 2012		x	x			x		France
Heys 2012				x	x		x	Nepal
Ho 2012			x			x	x	Australia, Canada, New Zealand, South Africa, UK, and USA
Hwang 2015			x			x		Singapore
Kissel 2014				x		x		USA
Kite 2011			x	x		x		Australia
Knott 2006			x			x		UK
Lee 2008			x			x		USA
Miller-Gairy 2015				x	x	x		USA (Somali refugees living in the USA)
Minhas 2015				x			x	Pakistan & India
Moodie-Dyer 2014				x		x		USA
Ooi 2016		x				x		Singapore
Qian 2012		x	x	x			x	China

	ICF-CY components					Country classification		
	Body structures	Body functions	Activities & participation	Environmental factors	Personal factors	HIC	LMIC	Country
Quilendrino 2015		x	x	x			x	Phillippines
Rosenberg 2012			x	x		x		Israel
Salkas 2016					x	x		USA
Sasaki 2015			x			x		Japan
Sotgiu 2011				x	x	x	x	Italy and Cuba
Twyman 2009			x			x		USA
Wang 2013				x	x	x		USA (Asian immigrants)
Whitaker 2007				x		x		UK

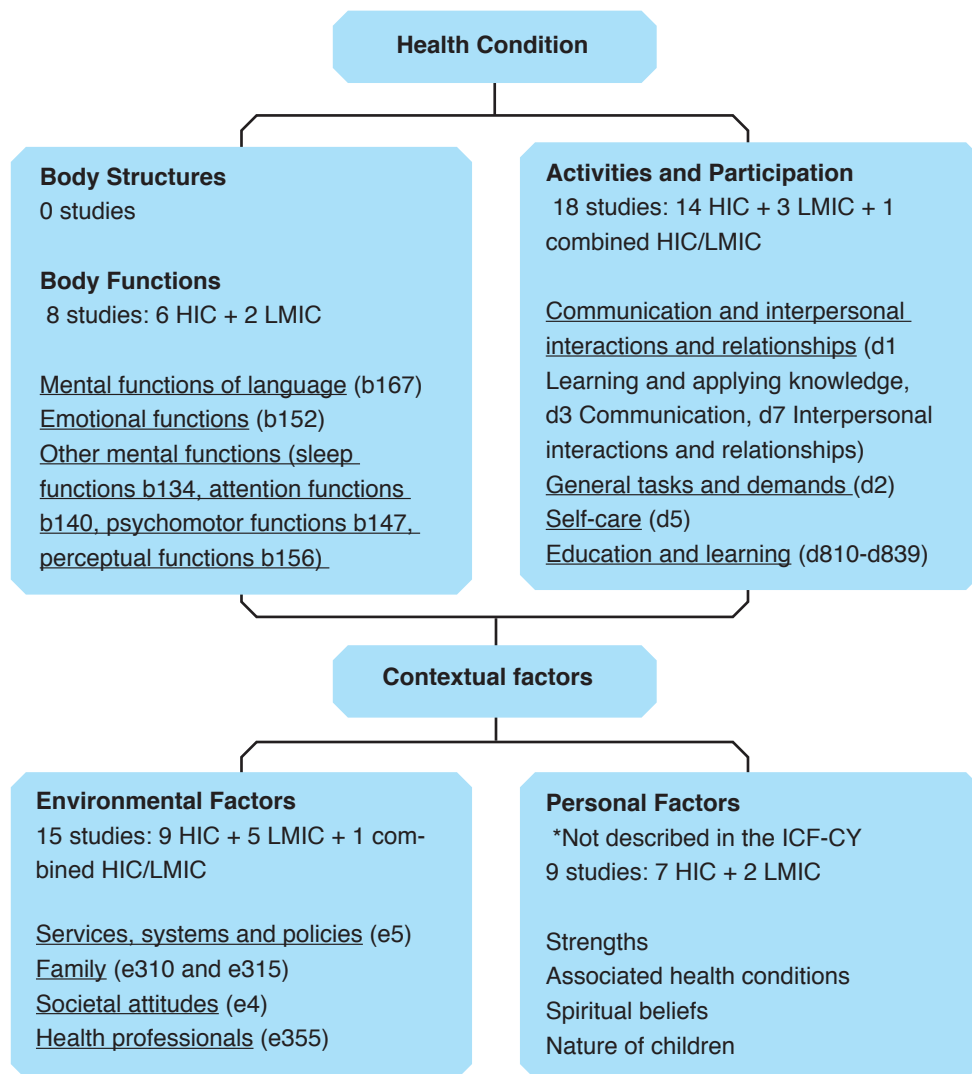


Figure 2.2 Parental perceptions of functioning in their children with ASD summarized by ICF categories

2.3.2 Linking to ICF categories

It was sometimes difficult to link the themes from identified articles clearly to only one specific ICF component. Articles were therefore often linked to more than one ICF category. Eight articles referred to body functions, seventeen to activities and participation, fifteen to environmental factors, and thirteen to personal factors. No article referred to body structures. Figure 2.2 shows a summary of the linking of key findings to ICF categories.

2.3.2.1 Body structures

None of the identified articles referenced body structures. One article (Quilendrino et al., 2015) mentioned that parents had a general idea that genes as well as the environment played a role in the presentation of ASD. Genes are however not classified in the ICF.

2.3.2.2 Body functions

Eight studies were identified that explored parental perception of body functions. Six of these studies were from HIC countries (UK, USA, France and Singapore) (Adamson, O'Hare and Graham, 2006; Guinchat et al., 2012; Barnhill et al. 2000; Coonrod and Stone, 2004; Azad and Mandell, 2016; Ooi et al., 2016) and two from LMIC counties (China and Philippines) (Qian, Chle and Bogenschutz, 2012; Quilendrino et al., 2015). All identified articles under body functions related to the chapter of 'mental functions', a broad chapter including functions of the brain. The common themes of mental functions of language, emotional functions and other mental functions are identified and are discussed below (see figure 2.2).

Mental functions of language

Parents were most worried by an absence of language, delay in speech or social interaction (discussed under activities and participation). Other behaviours characteristic of ASD, such as echolalia, restricted, repetitive and stereotyped behaviors, or general behavior problems, or even problems related to language comprehension, were less concerning to them (Coonrod and Stone, 2004; Guinchat et al., 2012; Azad and Mandell, 2016). All the above articles were from HIC, and mental functions of language were not discussed in any articles from LMIC.

Emotional functions

Aggression, anxiety, depression and adaptability were identified by parents as emotional concerns (Barnhill et al., 2000). In some cases children reportedly rated themselves as having higher levels of anxiety than their parents rated them (Guinchat et al., 2012; Ooi et al., 2016). All the above were from HIC. Emotional functions were not discussed in any of the articles from LMIC.

Other mental functions

Several other mental functions such as hyperactivity or attention difficulties, sleeping problems, repetitive stereotyped patterns of behaviours and perception abnormalities were of concern to parents from both HIC and LMIC (Barnhill et al., 2000; Guinchat et al., 2012; Qian, Chle and Bogenschutz, 2012; Quilendrin et al., 2015; Azad and Mandell, 2016). Parents also reported that their children were more sensitive to auditory stimuli than other children (Adamson, O'Hare and Graham, 2006). No obvious differences between HIC and LMIC were identified in this section.

2.3.2.3 Activities & participation

Eighteen studies were identified that examined parental perceptions related to activities and participation. Fourteen of these studies were from HIC countries (USA, Canada, France, Singapore, Australia, Israel and Japan) (Barnhill et al., 2000; Coonrod and Stone, 2004; Knott, Dunlop and Mackay, 2006; Lee et al., 2008; Twyman et al., 2009; Brown et al., 2011; Goodman, 2011; Kite, Tyson and Gullifer, 2011; Cavalari and Romanczyk, 2012; Guinchat et al., 2012; Rosenberg et al., 2012; Hwang et al., 2015; Sasaki et al., 2015; Azad and Mandell, 2016), three were from LMIC countries (Jordan, China and the Philippines) (Qian, Chle and Bogenschutz, 2012; Abu-Hamour and Muhaidat, 2014; Quilendrin et al., 2015) and one study assessed data from both a LMIC and HIC (Ho, Stephenson and Carter, 2012). Amongst the identified articles the common themes that emerged included communication, language, interpersonal interactions and relationships, general tasks and demands, self-care, and education and learning. These are outlined in more detail below.

Communication and interpersonal interactions & relationships

This section combines three ICF chapters namely chapter 1 - learning and applying knowledge (specifically the acquiring language section); chapter 3 - communication and chapter 7 - interpersonal interactions and relationships (see figure 2.2). They were grouped together as they all describe aspects of functioning relating to social interaction and are discussed together in most articles.

The most common concerns for parents were deficits in social interaction, communication and conversation skills (Barnhill et al., 2000; Coonrod and Stone, 2004; Knott, Dunlop and Mackay, 2006; Guinchat et al., 2012; Qian, Chle and Bogenschutz, 2012; Quilendrin et al., 2015; Azad and Mandell, 2016). Language development (or language acquisitions skills) and social interaction were the most common concerns first noticed by parents (Coonrod and Stone, 2004; Twyman et al., 2009; Guinchat et al., 2012; Qian, Chle and Bogenschutz, 2012; Quilendrin et al., 2015; Azad and Mandell, 2016). Coonrod and Stone (2004) argued that these results suggest that the earliest concerns experienced by parents of children with autism are not necessarily different to concerns of parents of children with developmental delays who also identified language development as their first concern. Twyman et al. (2009) reported that parents of children who received an earlier diagnosis observed difficulties with social development earlier than parents of children who only received a diagnosis later. Based on these studies the most common general concerns and the most common first concerns were the same for parents in HIC and LMIC.

Although parents reported that their children's social skills contribute to their social problems, they also recognized other areas of functioning such as aggression, anxiety, depression and adaptability as having a significant impact on social interaction (Barnhill et al., 2000). Parents perceived their children to have difficulty with basic interpersonal interactions such as understanding thinking, fear, desire and loneliness in others (Kite, Tyson and Gullifer, 2011).

General tasks and demands

Children's ability to manage their own behaviour, carry out a daily routine as well as handle stress and other psychological demands were of concern to parents. Parents reported that their children with ASD frequently presented with aggressive behaviours when angry and were not able to control their behaviour during angry episodes (Knott, Dunlop and Macky, 2006; Ho, Stephenson and Carter, 2012). One parent reported that there have been times when they had to physically restrain their son (Kite, Tyson and Gullifer, 2011). Antecedents for the episodes included changes in routines/ environments and inaccessibility of preferred items. The aggressive behaviour often impacted on the whole family (siblings, parents and child with ASD) (Ho, Stephenson and Carter, 2012). Problem behavior was identified as the second biggest concern for parents of school-going children with ASD (Azad

and Mandell, 2016), while parents in Jordan mentioned behavioural skills as necessary for inclusion in public schools (Abu-Hamour and Muhaidat, 2014). Some parents indicated that their children's behaviors resulted in them being expelled from school.

Parents of children with high functioning ASD were more concerned about their children's challenging behaviour than the key characteristic of ASD (Knott, Dunlop and Mackay, 2006; Kite, Tyson and Gullifer, 2011). Some parents were very concerned over their child's ability to cope with stress (Lee et al., 2008).

Based on the above results, management of behaviour were reported as concerns in school-going children in both HIC and LMIC. Further comparison of general tasks and demands in HIC and LMIC countries was not possible since it was only mentioned in one study from a LMIC country (Abu-Hamour and Muhaidat, 2014).

Self-care

Parents reported that their children with ASD experienced difficulties in completing basic daily activities (Guinchat et al., 2012; Sasaki et al., 2015) and self-help activities were listed by a small number of parents as their biggest concern for their school-going children with ASD (Azad and Mandell, 2016).

Concerns for their child's physical safety were also raised by parents. Children with ASD were rated by parents as engaging in more risk-taking behaviours and being likely to sustain more frequent and severe injuries than their peers. Children with better communication skills were perceived as at lower risk for injury, possibly because they can better understand and follow home safety rules (Cavalari and Romanczyk, 2012).

Children's independence impacted on families, and families of children who were more independent at home, school, or in the community reported fewer unmet needs than families of children with less functional independence (Brown et al., 2011). Self-care was not discussed in any articles from LMIC.

Education and learning

Items discussed under this heading are a combination of two ICF chapters, namely 1) learning and applying knowledge and 2) major life areas, which includes education, amongst others.

While the majority of parents from both HIC and LMC were supportive of inclusion in mainstream education (Kite, Tyson and Gullifer, 2011; Abu-Hamour and Muhaidat, 2014) articles indicated that children with ASD had more difficulties at school from the parents' viewpoint. They were reportedly more likely to miss school, be expelled from school and less likely to participate in organized activities than their peers (Lee et al., 2008). Parents recommended independence skills, playing skills, behavioural skills, imitation skills, routine skills, social skills, attention skills, language skills, and pre-academic/academic skills as necessary for successful inclusion (Abu-Hamour and Muhaidat, 2014). Not all parents were concerned about their children's academic abilities (Azad and Mandell, 2016).

2.3.2.4 Environmental factors

Fifteen studies were identified under the category of Environmental Factors. Nine of these studies were from HIC countries - USA, UK, Australia and Israel (Whitaker 2007; Kite, Tyson and Gullifer, 2011; Brookman-Frazee et al., 2012; Rosenberg et al., 2012; Gilligan, 2013; Wang and Casillas, 2013; Kissel and Nelson, 2014; Moodie-Dyer et al., 2014; Miller-Gairy and Mofya, 2015), five from LMIC countries - China, Kenya, Pakistan/India, Nepal and the Philippines (Qian, Chle and Bogenschutz, 2012; Minhas et al., 2015; Quilendrino et al., 2015; Gona et al., 2016; Heys et al., 2016), and one examined data from both LMIC and HIC - Cuba and Italy (Sotgiu et al., 2011). Amongst the identified articles common themes emerged around services, systems and policies, family, societal attitudes, and health professionals (see figure 2.2).

Services, systems and policies

Services, systems and policies from the educational and health sector were mentioned here.

In LMIC lack of services and the financial burden associated with accessing available services were themes that emerged. Gona and colleagues mentioned that parents on the Kenyan coast would rather send their child to a boarding school than keep them at home to ensure that they have better access to services (Gona et al., 2016). A study conducted in India and Pakistan reported that specialist services are rare, concentrated in urban areas, and inaccessible to most people (Minhas et al., 2015). The cost of accessing health services, the financial burden that places on families, and long waiting periods were mentioned by many as a hindrance to accessing services (Kite, Tyson and Gullifer, 2011; Qian, Chle and Bogenschutz, 2012; Quilendrino et al., 2015;

Gona et al., 2016). Due to the lack of any state-provided social care system, parents in India/Pakistan also expressed concern about the care of their children once the parents pass away (Minhas et al., 2015).

In HIC service system issues were perceived as barriers to access to health services (Brookman-Fraze et al., 2012; Wang and Casillas, 2013) with parents describing the process of accessing services as 'very stressful' and specifically reporting not understanding the service system and which service(s) to use at which point in their journey. Parents also reported system disconnects, financial challenges, logistical challenges and lacking information as barriers to access (Moodie-Dyer et al., 2014). Parents in a focus group discussion in Australia also reported a lack of available government services in regional/rural areas (Kite, Tyson and Gullifer, 2011).

Quality of care within health services was another issue raised in mostly HIC, where parents reported factors such as high clinic staff turnover, delays in diagnosis, inadequate service providers and feeling devalued by experts, impacting the consistency and effectiveness of care (Brookman-Fraze et al., 2012; Moodie-Dyer et al., 2014).

Parents in the USA reported positive experiences when accessing and receiving health services and mentioned collaboration, communication, financial resources, high quality services, insider knowledge and parent–caregiver provided care as factors contributing to positive experiences (Moodie-Dyer et al., 2014). The majority of parents taking part in a study examining educational services and systems in the UK reported that they were satisfied with the provision being made for their children. Perceived flexibility of schools in response to their children's needs, communication between home and school and feeling understood by school staff contributed to their satisfaction (Whitaker, 2007).

Family

The importance of family and friends was evident in several articles, particularly in LMIC. Parents, or close family and friends, are reportedly the first to notice most of the signs of ASD in Pilipino children (Quilendrin et al., 2015). Minhas reported that poor ASD awareness in family members leads to delay in recognition and appropriate management in Indian and Pakistani families (Minhas et al., 2015). The burden of care largely fell on the family in LMIC such as in India, Pakistan and China (Qian, Chle and Bogenschutz, 2012; Minhas et al., 2015).

Sotgiu examined parental perspectives cross-culturally by comparing Italian mothers' attitudes/perspectives to those of Cuban families. Italian children appeared to have more extensive social networks due to the involvement of more figures such as social workers, pediatricians and therapists. Cuban children's social networks were smaller, but they were reported to have more multifunctional figures and greater frequency of contact with members of their networks (Sotgiu et al., 2011).

Societal attitudes

Societal attitudes are opinions and beliefs generally held by people of a social group (culture, society, subcultural) about other individuals or about other social, political and economic issues. These beliefs and opinions influence group or individual behaviour and actions (World Health Organization 2001, 2007).

Stigma was a theme that emerged mostly in studies from LMIC. It was discussed in four (of six) studies from LMIC countries (Gona et al., 2016; Heys et al., 2016; Minhas et al., 2015; Qian, Chle and Bogenschutz, 2012) and only one study from a HIC, which looked at perceptions of a South-Asian Muslim community in the UK (Gilligan, 2013).

Children with ASD and their families were reportedly stigmatized and even discriminated against in certain communities. The opinions of the community were often described by parents from HIC and LMIC as stemming from the general lack of awareness of ASD (Gilligan, 2013; Minhas et al., 2015; Gona et al., 2016). Several studies from LMIC and one from a HIC reported that parents were blamed for their child's condition with in-utero stressors, birth complications, parenting style and home environment listed as possible causes of developmental difficulties (Gilligan, 2013; Gona et al., 2016; Heys et al., 2016). Stigma reportedly had a restricting impact on the lives of many children with ASD and their families which might result in them waiting longer to seek diagnosis and intervention. Some families in LMIC worried about the mistreatment of individuals with ASD by community members (Qian, Chle and Bogenschutz 2012; Minhas et al., 2015). According to findings from this scoping review societal attitudes (stigma) seems to be more prevalent in LMIC than HIC. Causes for stigma such as lack of public awareness and knowledge however seem to be similar in HIC and LMIC.

Health professionals

Lack of knowledge from health professionals were described in several studies in both HIC and LMIC countries. Brookman-Frazee reported that parents perceived child mental health services in the USA to be negatively affected by the lack of therapist and psychiatrist knowledge about treating children with ASD (Brookman-Frazee et al., 2012). Parents in the USA also reported feeling devalued by experts (Moodie-Dyer et al., 2014). In Nepal, India and Pakistan health professionals reportedly had poor awareness of autism leading to delays in diagnosis and lack of appropriate management (Minhas et al., 2015; Heys et al., 2016). Gona reported that lack of information from health professionals increased chances of parents engaging in searches for alternative treatment. Most parents of children with ASD on the Kenyan coast had visited a traditional healer regardless of religious beliefs (Gona et al., 2016). A study examining the experience of Somali mothers receiving treatment in the USA reported that mothers felt service providers failed to understand their culture resulting in poor communication and low expectations for treatment (Miller-Gairy and Mofya, 2015). Parents' perceptions with regards to health care professionals were similar in HIC and LMIC countries with dissatisfaction with professional knowledge about ASD and attitudes of health care professionals being raised in both settings.

Similar themes around parents' dissatisfaction with health care professionals were raised in both HIC and LMIC.

2.3.2.5 Personal factors

Ten studies were identified under the category of personal factors. Seven of these were from HIC countries - USA and UK (Barnhill et al., 2000; Brookman-Frazee et al. 2012; Bal and Radke, 2013; Gilligan, 2013; Wang and Casillas, 2013; Miller-Gairy and Mofya, 2015; Salkas et al., 2016), two from LMIC counties - Kenya and Nepal (Gona et al., 2016; Heys et al., 2016), and one study that examined data from both LMIC and HIC - Cuba and Italy (Sotgiu et al., 2011). Two of the seven studies from HIC countries examined personal factors relating to immigrant or refugee populations (Miller-Gairy and Mofya, 2015; Wang and Casillas, 2013).

Many studies referred to personal factors relating to the parents, as opposed to parents' perception of how personal factors influence and relate to their children. This might be because the impact of many personal factors such as background, upbringing and lifestyle might only be visible in children at a

later age. Other factors such as character, habits and coping styles are still developing and are difficult to accurately assess and comment on in such a young population.

Several studies from both HIC and LMIC examined parents' beliefs regarding ASD, its origin and how culture and/or other personal factors impact the way parents think about ASD. While parental perception of ASD will influence their perception of their child and his/her functioning and subsequently the way they treat their child, the focus of this study was parental perception on functioning specifically. Articles discussing general parental perceptions on ASD and not ASD and functioning were therefore not included in this review.

Strengths

Strengths were only mentioned in studies from HIC. Parents described intelligence and sense of humour (Brookman-Frazee et al., 2012), while parents of children with high functioning ASD reported empathy, sensing fairness, and storytelling to be their children's biggest social strengths (Bal and Radke, 2013).

Associated health conditions

The most frequently mentioned associated health conditions were ADHD, anxiety disorders, and mood disorders such as depression (Barnhill et al., 2000; Brookman-Frazee et al., 2012). No study from a LMIC mentioned any associated health conditions.

Spiritual beliefs

Spiritual beliefs were discussed by studies from both LMIC and HIC. One of the two studies from HIC explored an immigrant population.

It was important for many Muslim parents to ensure that their children can meet religious requirements (Gilligan, 2013). Parents often used a combination of their religious beliefs and Western evidence-based practices to benefit their children. This was the case for parents from many different cultures and religions including Christianity, Buddhism, Taoism or Confucianism (Wang and Casillas, 2013; Gona et al., 2016).

Nature of children

Some parents commented on the nature or character of their children and attributed some of their children's ASD symptoms to personal factors like

stubbornness, shyness, unruly behaviour or other traits they would grow out of (Miller-Gairy and Mofya, 2015; Heys et al., 2016). Somali mothers living in the USA felt that they and their children were discriminated against in schools because of their race, resulting in these families not trusting the school system (Miller-Gairy and Mofya, 2015).

Social background

According to Sotgiu and colleagues (2011) the nature of the culture in which children live has an impact on the size and quality of their social network. Cuban children's networks are smaller, but consist of more multifunctional figures, with whom they have more frequent contact. Italian children's networks are generally larger, but a lot of the people present play a supportive role, such as social workers, pediatricians. Some parents from a HIC perceived their own parenting habits to be the most restricting factor at home (Rosenberg et al., 2012). No other articles from either HIC and LMIC were identified and no further comparison could therefore be made.

2.4 Discussion

ASD is a global phenomenon, yet it is well established that functional ability and disability is influenced by the context an individual lives in. Parental perspectives of the functional impact of ASD on their children's lives represent key information in the planning of assessment and treatment for ASD. Given that no previous studies have aimed to integrate parental perspectives of functioning in ASD across the globe, we set out to perform a scoping review to examine this question. We firstly set out to get a general sense of where research on parental perspectives of functioning had been performed, what themes and methods were used, and, in particular, to see how many studies came from HIC and LMIC. Secondly, we set out to link the themes from identified publications to the ICF framework of functioning in order to examine the similarities/differences of functional themes raised in HIC vs LMIC using a well-established conceptual framework.

We predicted that we would find more studies from HIC in comparison to LMIC. We also expected studies from LMIC to be mostly concerned with environmental factors, whereas literature from HIC would discuss

environmental factors as well as categories from other ICF components namely body structures, body functions and activities and participation.

A total of 33 appropriate studies were identified. As predicted, most studies were conducted in HIC (n = 27, 82%) and only six studies from LMIC were identified. North America was the biggest contributor from HIC (n=16) and Asia for LMIC (n=4). Two studies compared views from HIC and LMIC countries. Key findings were summarized per ICF categories namely body structures, body functions, activities and participation, environmental factors and personal factors. Under each of these categories themes were grouped per ICF chapters where possible.

As hypothesized, studies from LMIC mostly discussed environmental factors and had little information on themes classified under body structures, body functions and activities & participation. Where body functions and activities & participation were discussed in articles from LMIC it mostly examined parents' early concerns, except for one article that focused on parental concerns around education (Abu-Hamour 2013). While it was positive to see articles from LMIC examining early concerns and environmental factors, the lack of information on other areas was striking. Due to the lack of research from LMIC, it would be wrong to assume that parents from these countries do not perceive their children to have difficulties in other areas of functioning. We propose that it is more likely that this is indicative of a research gap highlighting the need for more research concerning all areas of functioning to be conducted in LMIC. Articles from HIC examined a much broader range of categories and covered all ICF categories.

Communication, interpersonal interaction and relationships were mentioned by parents from HIC and LMIC as their earliest concerns. Findings suggest that the most common early parental concerns were not necessarily specific to ASD, which may be one of the reasons why these warning signs are often overlooked and sometimes dismissed by parents and health professionals. Being aware of early warning signs and taking the appropriate action at the appropriate time is crucial to ensure that early assessment and intervention is accessed and implemented. The benefits of early intervention are well-documented (Lovaas, 1987; Smith, Groen and Wynn, 2000; Dawson, 2008; Dawson et al., 2010; Sacrey, Bennett and Zwaigenbaum, 2015). Increased awareness about early signs of ASD among parents and health professionals should therefore

be prioritized. The above studies suggested that ASD awareness campaigns globally could benefit from an increased focus on language skills and social interaction rather than on other autism-specific behaviours.


While parents' early concerns were related to language development and social interaction, challenging behaviour became more of a concern when children were older, specifically if they were higher functioning. Parents' main concerns in the area of education and learning were often more linked to concern about social interaction and behavior, rather than academic skills. While parental perceptions may well be different from those of teachers, the observation raises the importance of educational systems to consider social interaction and behavioural difficulties in the school setting alongside academic achievement.

Due to lack of health services in LMIC in comparison to HIC it can be assumed that children living in LMIC will have fewer health professionals or professional support present and subsequently smaller social networks, as described by Sotgiu. While this does place a bigger burden of care on families, it also provides a context for health providers when developing and planning intervention strategies in lower socio-economic settings. Intervention strategies that can utilize the family and community may be more appropriate, realistic and likely to be successfully implemented than strategies that rely heavily on health professionals that are often scarce or even absent in these settings (Guler et al., 2017). Examples include parent-coaching programs (Bello-Mojeed et al., 2016; Rahman et al., 2016; Blake et al., 2017) where parents are coached by health professionals in basic principles and implementation of intervention strategies. Parents can then implement these strategies at home, with support from professionals, as part of daily living activities.

The isolating impact of stigma was mentioned mostly by families in LMIC settings. The one study from a HIC that did discuss stigma looked at an immigrant population living in a HIC. General lack of ASD awareness was identified by individuals in both LMIC and HIC as a cause of stigma. Families in LMIC settings are more reliant on the community due to lack of resources, but stigma can prevent them from getting the support they need. In addition to stigma in these communities, health professionals also reportedly had poor knowledge of ASD (Minhas et al., 2015; Gona et al., 2016; Heys et al., 2016), which means that even when parents do have access to professional services they might receive inadequate support. The individual attitudes of

health professionals in areas characterized by stigma might also be negatively influenced due to the impact of society on the health professional's views. This highlights the need for increased awareness in LMIC and HIC, both in the general public and amongst health professionals.

2.5 Limitations

We acknowledge a number of limitations of this scoping review. While we took great care to screen all articles relating to parental perceptions in relation to ASD and functioning, we recognize that articles could have been missed due to the specific search terms that were used. Articles discussing broader themes could also have included aspects of parental perception that would not have been identified. We also acknowledge that the inclusion of only English publications may have excluded potentially relevant publications, particularly from LMIC. However, given existing resources, it would not have been possible for us to have sourced and translated all non-English publications. 

2.6 Conclusion

As predicted, the majority of peer-reviewed research on parental perceptions of functioning in ASD over the last 2 decades has come from high-income countries, even though most children with ASD live in LMIC. Functional themes from HIC included a range across the ICF biopsychosocial framework with body functions, activities & participation, environmental factors and personal factors all represented. Functional themes from LMIC were more typically focused on environmental and personal factors thus making direct comparison across ICF categories difficult. We propose that further research should consider a more systematic comparison of HIC and LMIC across functional categories in order to get a more accurate impression of the impact of context on functioning in ASD.

CHAPTER 3

How does context influence functioning in children with ASD? A comparison of parent/caregiver perceptions from a Low/Middle-income Country (LMIC) and a High-Income Country (HIC)

3.1 Background

Autism Spectrum Disorder (ASD) is heterogeneous in nature and functional outcomes can be very different in different individuals (Abrahams and Geschwind, 2008; Masi et al., 2017). As outlined in chapter 1, we also know that functioning is strongly influenced by context that may have a strong modifying role on ability and disability (Verbrugge and Jette, 1994; Oliver, 1998). In this study we were particularly interested in the functional impact of ASD on children from different socio-economic settings as perceived by parents/caregivers.

Results from the scoping review (chapter 2) identified significantly fewer peer-reviewed articles from low/middle-income countries (LMIC, n=6) than from high-income countries (HIC, n=27). Only 33% (two of six) studies from LMIC explored themes around body functions, 50% (three of six) activities & participation while 83% (five of six) of studies were concerned with environmental factors. In contrast, 66% of studies from HIC covered aspects of activities and participation, 55% environmental factors and 30% body functions. These results support previous studies as summarized by Franz and colleagues (2017) that found the majority of research on ASD originated from HIC and focused on themes of relevance to HIC. The scoping review suggested that environmental factors may be of greater importance or significance in LMIC settings than in HIC settings. However, one of the challenges of the scoping review was the fact that studies from HIC and LMIC had widely different aims, objectives and methodologies. It is therefore possible that the apparent differences observed may have been coincidental. The existing literature on parent/caregiver perceptions of ability and disability in ASD to date therefore has not allowed for a direct and systematic comparison of functioning between HIC and LMIC settings.

In this phase of the study, we therefore set out to do a deliberate comparison of parent/caregiver perceptions from HIC and LMIC settings, using identical interview guides for qualitative data collection. We used the WHO ICF framework to identify themes in the scoping review, but acknowledged that none of the primary papers included in the review expressly use any specific theoretical framework of functioning to structure or evaluate questions. For this reason, we therefore decided to base our systematic comparison on the ICF biopsychosocial framework and set out to use a methodology that overtly used the ICF framework for data collection.

The ICF is widely used to measure functioning and recent efforts have been made to develop ICF 'core sets' for ASD (Bölte et al., 2014). This process included a systematic review of existing literature and an expert survey (de Schipper et al., 2015; de Schipper et al., 2016). Very appropriately the process also had a deliberate step to include parent/caregiver perceptions of functioning (Bölte et al., 2014; Mahdi et al., 2017), during which focus group discussions and individual interviews were conducted in a range of HIC and LMIC. Focus group and individual interview discussions were facilitated by asking all participants the same questions as specified by the standardized WHO ICF branch Core Set Development Protocol (Bölte et al., 2014) (appendix A).

The overarching question of the work here was to examine the universality of functional ability and disability in ASD. That is, we were interested to know whether functional themes raised in different contexts would be similar or different. We selected to use the ASD ICF Core Set Development process to determine whether items identified in the qualitative phase of the ASD ICF core set were universally reported across HIC and LMIC, or whether there may have been uniquely different profiles of functional ability and disability associated with different settings.

During the core set development process data from the 5 participating countries (South Africa, Sweden, Saudi Arabia, India and Canada) were pooled. Whilst it was extremely important and valuable that a range of global data were incorporated into the process and decision-making around ICF core sets for ASD, we expressed concern that pooling data from across the globe, including African data, may have led to an 'averaging out' of the functional consequences of ASD in different regions of the world, particularly given the fact that functioning, ability and disability is highly influenced by context (Mahdi et al., 2017).

The purpose of this part of study was therefore to examine the impact of the context on functional ability and/or disability in children with ASD based on parent/caregiver perceptions of functioning by deliberately comparing and contrasting two of the most divergent countries who participated in the core set development project.

3.1.1 Sweden and South Africa as examples of HIC and LMIC

For this study we used World Bank income groupings where member states are grouped into low/middle-income countries (LMIC) or high-income countries (HIC) (The World Bank, 2017a). For the purposes of this study, Sweden was selected as an example of a high-income country (HIC) and South Africa as an example of a low/middle-income country (LMIC). Sweden and South Africa differ vastly not only in socio-economic status, but also in terms of health and education services, systems and policies, as discussed below.

Sweden has an estimated population of 9.8 million and the seventh-highest per capita income in the world, hence its HIC classification. A 2012 study found the prevalence of children with ASD in Sweden to be about 1% (Nygren et al., 2012). In Sweden screening for ASD is widely available. A study in the Gothenburg area reported that almost 100% of two and a half year old children are targeted in annual screening at clinics as part of the AUDIE (Autism Detection and Intervention in Early life) project (Carlsson et al., 2016). Identified high risk infants have access to basic early intervention services and parent education. Children diagnosed with ASD in Sweden have access to free Early Intensive Behavioural Intervention (EIBI) services. These services are provided by both county-based health care systems and municipality-based education systems. The intensity, duration and content of treatment varies from child to child depending on their needs (Langh et al., 2017). Interestingly, despite the availability of intervention services in Sweden, parents reportedly do not necessarily feel supported and satisfied with the services they receive (Carlsson et al., 2016).

The Swedish school system is regulated through the Education Act (Stockholm Ministry of Education and Research, 2010). The act states that it is compulsory for all children to attend school for 9 years from age 7 to 16. Upper secondary schooling (16 - 19 years) is not mandatory, but is reportedly attended by most students. Compulsory schooling is free and students also have free access to one pre-school year before they commence their compulsory schooling. Pre-school for children aged 1-5 years is subsidized depending on the family's financial situation (Stockholm Ministry of Education and Research, 2010).

The Education Act also states that special support measures should be provided within the existing schooling system to accommodate learners with special needs, but there are no clear guidelines as to what this means. Special schools or 'sarskola' are available for children with severe intellectual or learning disability, but support for learners with difficulties are commonly provided outside the general classroom (Bolic Baric et al., 2016). There are a small number of independent schools in Sweden of which some are ASD-specific.

South Africa has an estimated population of 54.9 million and ranks 88th in the world per capita income rating. It is classified by the World Bank as an upper-middle income country. The majority of the South African population depend on the public healthcare system, which has limited physical, financial and human resources (Bloom and McIntyre, 1998 ; Kon and Lackan, 2008). South Africa also has some of the greatest health disparities of all countries in the world, and has a Gini coefficient of 0.65, which is higher than the average (0.45 to 0.63) for upper-middle income countries (The World Bank, 2017b).

There are currently very little data on the incidence, prevalence, and impact of ASD in Africa in general and in South Africa specifically. No epidemiological data of ASD in South Africa are available (Franz et al., 2017; Van Schalkwyk, Beyer and de Vries, 2016). In a recent databased study Pillay and colleagues found that ASD was under-identified in South Africa, that there are long waiting lists for ASD schools, and that co-morbidities associated with ASD are also highly under-identified (Pillay, Duncan and de Vries, 2017).

There are no legal mandates for ASD-specific services in South Africa. Nine schools in the country are specifically set up for learners with ASD, of which four are private and the remaining five government-funded. Six of these schools are located in the Western Cape province and the remaining three in Gauteng and Eastern Cape (Van Schalkwyk, Beyer and de Vries, 2016). Children with ASD may also have access to regular schools with special ASD programmes or special needs schools not specific to learners with ASD. Children under the age of 6 or 7 do not have access to public service early intervention or educational programmes due to the fact that no governmental preschools exist and no early intervention programmes are in place. The capacity to diagnose ASD in the public sector is limited due to limited number of qualified specialists and the availability of accurate diagnostic services in the private sector is not clear. Intervention services are also limited and often provided within the non-governmental organization (NGO) sector (Van Schalkwyk, Beyer and de Vries, 2016).

The table below shows a socio-economic comparison between Sweden and South African as reported by the Organization for Economic Co-operation and Development (OECD, 2017).

Table 3.1 Comparison of socio-economic factors in South Africa and Sweden

	Sweden	South Africa
Average household net-adjusted disposable income per year	28 859 USD	8 712 USD
Household financial wealth per capita *total value of a household's financial worth, such as money or shares held in bank accounts	69 899 USD	16 937 USD
Average earnings per year	40 994 USD	5 429 USD
Employment rate (15-64 years)	75%	42.8%
Long-term unemployment rate *percentage of the labour force that has been unemployed for a year or longer	1.3%	14.4%
Educational attainment *Percentage of adults aged 25-64 whom have completed upper secondary education.	82%	65%
Years in education	19.1 years	15.4 years
Life expectancy at birth	~82 years	~57 years
Percentage of people who believe that they know someone they could rely on in time of need	92%	90%
Life satisfaction *0-10 rating scale	7.3	4.9
Percentage of people reporting that they feel safe walking alone at night	77%	39.8%
Homicide rate	0.8	9.6
Average number of rooms per person	1.8 rooms per person	0.7 rooms per person
Dwellings with basic facilities *flushing toilet	100%	79.5%

3.1.2 Study rationale and hypotheses

Given the stark socio-economic differences between Sweden and South Africa, we set out to compare and contrast the functional impact of ASD in the two countries. We were interested in two related but distinct aspects of parent/caregiver perspectives in relation to functioning:

- 1) Comparing and contrasting the frequency of functional themes reported by parents/caregivers between Sweden (as HIC) and South Africa (as LMIC)

- 2) Comparing and contrasting the content of the functional themes reported by parents/caregivers between a HIC and LMIC setting

We hypothesised that:

- a) body structures and body functions (ICF categories from chapters 1 and 2) would show similar frequency of reporting by parents in LMIC and HIC settings given that body structures and functions describe the absolute or universal elements of ASD
- b) environmental factors (ICF categories from chapter 4) would be more frequently reported by parents in relation to functional impairment in LMIC settings than in HIC settings where environmental factors were hypothesized to be more facilitatory to functioning in ASD
- c) the content of themes from body structures and body functions (ICF categories from chapters 1 and 2) would be similar in direction (either facilitator or barrier) in LMIC and HIC settings
- d) the content of themes from environmental factors (ICF categories from chapter 4) would be different in direction (either facilitator or barrier) in LMIC and HIC settings

3.2 Methods

For the purpose of this study we performed secondary analysis of data collected during the qualitative phase of the ICF core set development process for ASD (Mahdi et al., 2017). Methodological details are outlined below.

3.2.1 Participants

Inclusion criteria for the original ICF core set development study was that participants had to be a caregiver, immediate family member or individual involved in the everyday life of someone with a diagnosis of ASD. The original study also involved individuals with a diagnosis of ASD, but, given our interest in parent/carer perspectives, data from this group were not included in this study. For details about the original study recruitment, consent and participants please see Mahdi et al. (2017). Participants were divided into stakeholder groups to ensure a balanced comparison between countries. Participants were therefore divided into 4 South African and 3 Swedish Stakeholder groups. For details and rationale for stakeholder grouping, please see Mahdi et al. (2017).

3.2.2 Procedures

Focus group discussions and individual semi-structured interviews for the original ICF core set study were conducted following predetermined ICF guidelines. Six questions covering all components of the ICF biopsychosocial model, and one question regarding strengths, guided the discussions (Appendix A). The original study (Mahdi et al., 2017) presented detail regarding focus group and interview procedures. We followed the prescribed steps (see appendix A) and used the recommended visual aids (see appendix B) during interview and focus group discussions. The author led all focus group and individual interviews in South Africa.

Focus group discussions and individual interviews were recorded, translated and transcribed following ICF guidelines as described in the original study manuscript (Mahdi et al., 2017). Meaningful concepts were extracted from the transcripts using qualitative content analysis and linked to ICF categories following ICF linking rules (Cieza et al., 2002; Cieza et al., 2005; Mahdi et al., 2017). Two independent coders, one from South Africa (the author) and the ASD Core Set project lead from Sweden, did coding and linking of all the South African focus group data. Previously coded Swedish data (for analysis for this study) and anonymous Swedish transcripts (for qualitative analysis) were provided to the South African team via a safe electronic platform, once all ethical approvals were in place.

3.2.3 Ethics

Ethical approval for the original study was granted by the Karolinska Institute Ethics Committee (reference number 2014/53-31/2, appendix K and appendix L) and by the University of Cape Town Human Research Ethics Committee (HREC reference 506/2015, appendix M). In addition, permission was granted by Red Cross War Memorial Children's Hospital for local data collection (appendix N), and by Dr David Griessel from the University of Free State, who led recruitment of participants from the second recruitment site in Bloemfontein (appendix O). Given that this study was for degree purposes, an additional UCT HREC was obtained (HREC reference 863/2016). We received written permission from the lead team at the Karolinska Institute to use anonymized Swedish and global data for this study (see appendix C). This study was conducted in conformity with the ethical principles of the Declaration of Helsinki.

3.2.4 Data analysis

3.2.4.1 Data analysis phase 1: Frequency Analysis

For frequency analysis we identified, ranked and compared similarities and differences in frequency of reporting from the coded South African and Swedish data. Second level ICF categories were used (see chapter 1.5 International Classification of Functioning) to ensure that this study was comparable to the overall ASD ICF qualitative study (Mahdi et al., 2017).

After identifying similarities and differences in frequency of reporting, South African and Swedish data were compared to the 'pooled global dataset', referring to data from all the participating countries (Canada, India, Saudi Arabia, South Africa and Sweden). The following steps were followed during the frequency analysis:

1. South Africa = Sweden: Identification of ICF categories reported in 100% (four of four) South African as well as 100% (three of three) Swedish groups.
2. South Africa \times Sweden: Identification of ICF categories with obvious differences in frequency of reporting between South Africa and Sweden. 'Obvious Differences' were operationalized to include categories that were present in three out of three Swedish groups and zero or one South African groups, or in two out of three Swedish groups but zero South African groups. For South African data it included categories that were present in four of four South African groups and zero or one Swedish groups, as well as three of four South African groups and zero Swedish groups.
3. South Africa/Sweden \times Pooled Global Data: Identification of ICF categories where South African and/or Swedish data were different to pooled global data. To do this we identified categories that were reported in 100% of groups from other countries, but in 50% (2/4) or less of South African groups or in 33% (1/3) or less of Swedish groups. We also identified categories that were reported only in South Africa and/or Sweden, but not in any group from any other country.

3.2.4.2 Data analysis phase 2: Content Analysis



The content of all ICF second level categories identified in the frequency analysis (phase 1) were analyzed to determine if they were mentioned as a facilitator or barrier to function. The process for content analysis is described below.

1. All meaningful phrases relating to all the ICF categories identified in the frequency analysis (see above) were extracted from the original South African and Swedish transcriptions. Text surrounding the meaningful concepts that might have enabled the researchers to better understand the context in which the meaningful phrase was mentioned were also extracted.
2. Meaningful phrases and surrounding text in Swedish were translated to English by the Swedish research team at the Karolinska Institute.
3. Swedish and South African meaningful phrases and surrounding text were independently analysed by two researchers (the author and the Swedish ICF project coordinator). Researchers read through transcripts and assigned a value describing the nature in which each meaningful phrase was mentioned in the data. The surrounding text was considered during this process. Where a meaningful phrase was mentioned as a factor that supports or improves the individual with ASD's functioning it was assigned a positive value (☑). For a meaningful phrase to be rated as a facilitator it had to have been described by parents/caregivers as unambiguously improving/supporting functioning in the individual with ASD. Where a meaningful phrase described a factor that lowered or had a limiting impact on functioning, it was defined as a barrier and assigned a negative value (☒). For a meaningful phrase to be rated a barrier it had to have been described by parents/caregivers as unambiguously limiting/reducing functioning in the individual with ASD. Where the meaning of a phrase was unclear or where there was uncertainty whether it was positive or negative a rating of '9' (unable to code) was given. After both researchers independently coded all the meaningful phrases they met to discuss differences in their coding and reach consensus. It was not necessary to consult a third party to reach consensus.
4. Once meaningful phrases were coded as barriers or facilitators the phrases for each ICF category were compared between South Africa and Sweden. ICF categories were defined as similar when all the meaningful phrases coded under that specific ICF category were mentioned in the same direction (facilitator or barrier). ICF categories were defined as different when more than two meaningful phrases coded under the specific ICF category were mentioned in a different direction.
5. Additional obvious emerging themes across categories were identified using thematic analysis.
6. Finally, exemplary meaningful phrases were extracted to illustrate perspectives.

3.3 Results

3.3.1 Demographic results

The overall study included 11 stakeholder groups (61 participants) from five countries (India, South Africa, Saudi Arabia, Canada and Sweden). Four stakeholder groups were from South Africa (22 participants), three from Sweden (13 participants), two from India (11 participants), one from Saudi Arabia (6 participants) and one from Canada (9 participants).

As per Mahdi et al (2017) participants were divided in stakeholder groups to avoid favouring the responses of interviewed participants. The three Swedish and four South African stakeholder groups represented 13 Swedish and 22 South African participants. The composition of these are outlined in table 3.2. The mean age of South African participants was 40 years. South African participants consisted of 72.7% (16 of 22) female participants and 27.3% (6 of 22) male participants. All participants were caregivers of children between the ages of 3 and 18 years. The mean age of Swedish participants was 48 years. Swedish participants were also mostly female (84.6%, 11 of 13).

3.3.2 Frequency of ICF categories reported in Sweden and South Africa

3.3.2.1 Categories present in 100% of South African and Swedish groups

Four ICF categories were identified that were reported in 100% (four of four) South African as well as 100% (three of three) Swedish groups. These included three categories under activities & participation namely carrying out daily routine (d230), dressing (d540), and complex Interpersonal Interactions (d720) and one

Table 3.2 Summary table and schematic representation of South African and Swedish parent/caregiver stakeholder groupings

Sweden	South Africa
Stakeholder group 1 Focus group 1 (4 participants)	Stakeholder group 1 Focus group 1 (8 participants)
Stakeholder group 2 Focus group 2 (4 participants)	Stakeholder group 2 Focus group 2 (5 participants)
Stakeholder group 3 Individual semi-structured interview 1 Individual semi-structured interview 2 Individual semi-structured interview 3 Individual semi-structured interview 4 Individual semi-structured interview 5	Stakeholder group 3 Focus group 3 (4 participants)
	Stakeholder group 4 Focus group 4 (5 participants)

category from environmental factors namely immediate family (e310). All of the categories, apart from dressing, were also present in all stakeholder groups in the pooled global data. That is, 100% of the groups that were part of the global study mentioned these three categories. Results are summarized in table 3.3.

3.3.2.2 Obvious differences between South Africa and Sweden

Ten ICF categories with obvious differences in frequency of reporting between South Africa and Sweden were identified. A total of six categories were identified under body functions, three under activities & participation and one under environmental factors. Obvious differences between South Africa and Sweden are shown in figure 3.1. Categories mentioned in more South African than Swedish groups included orientation functions (b114), basic cognitive functions (b163), mental functions of language (b167), managing one’s own behaviour (d250), speaking (d330), and health professionals (e355). Categories mentioned in more Swedish than South African groups included attention functions (b140), involuntary movement functions (b765), gait pattern functions (b770) and undertaking a single task (d210). Results are summarized in table 3.3.

3.3.2.3 Differences between South Africa and/or Sweden compared to global data

Twenty categories were identified where South African and/or Swedish data were very different to pooled global data. These categories are shown in figure 3.2. Five categories were identified under body functions, nine under activities & participation and six under environmental factors.

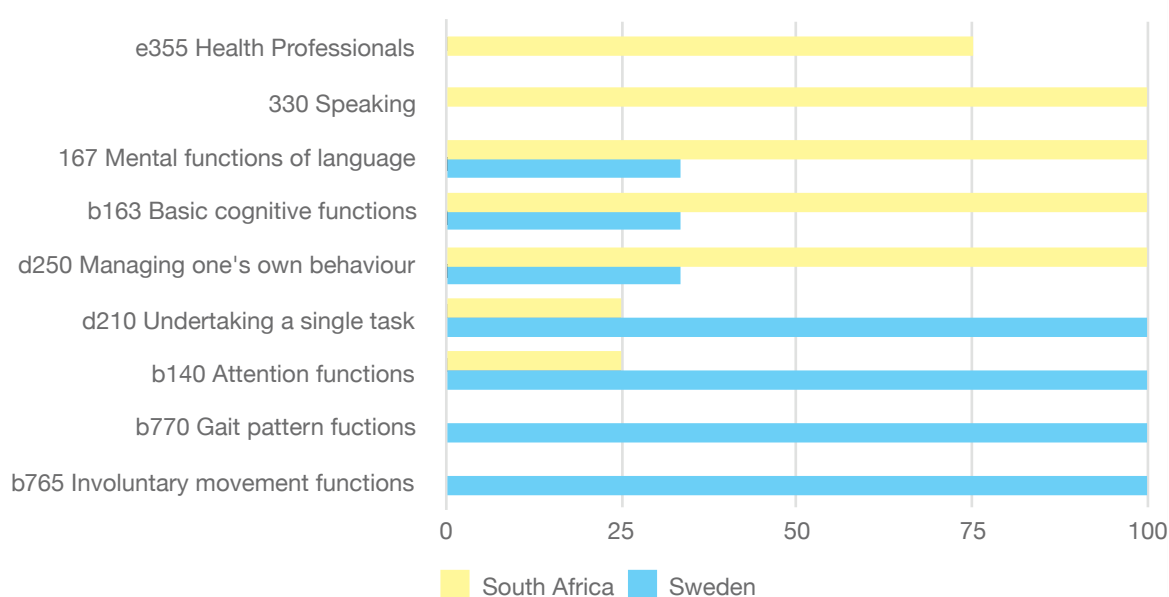



Figure 3.1 Obvious differences in frequency of reporting between South Africa and Sweden.

Categories mentioned in all global groups except South Africa and Sweden were sleep functions (b134) and family relationships (d760). Categories mentioned in all global groups, except in some South African groups were school education (d820) and products and technology for personal use in daily living (e115).

Categories mentioned only in groups from South Africa and Sweden but not in any other countries were perceptual functions (b156), thought functions (b160), experience of self and time functions (b180), sensory functions related to temperature and other stimuli (b270), using communication devices and techniques (d360), products and technology for education (e130) and individual attitudes of health professionals (e450).

Categories mentioned only in South African data and not in data from any other country were acquiring concepts (d137), looking after one's safety (d571), **complex interpersonal interactions (d720)**, ic economic transactions (d860), social norms, practices and ideologies (e465), and transportation services, systems and policies (e540). Categories mentioned only in Swedish groups and not in any group from any other country were making decisions (d177), conversation (d350), and air quality (e260). Results are summarized in table 3.3.

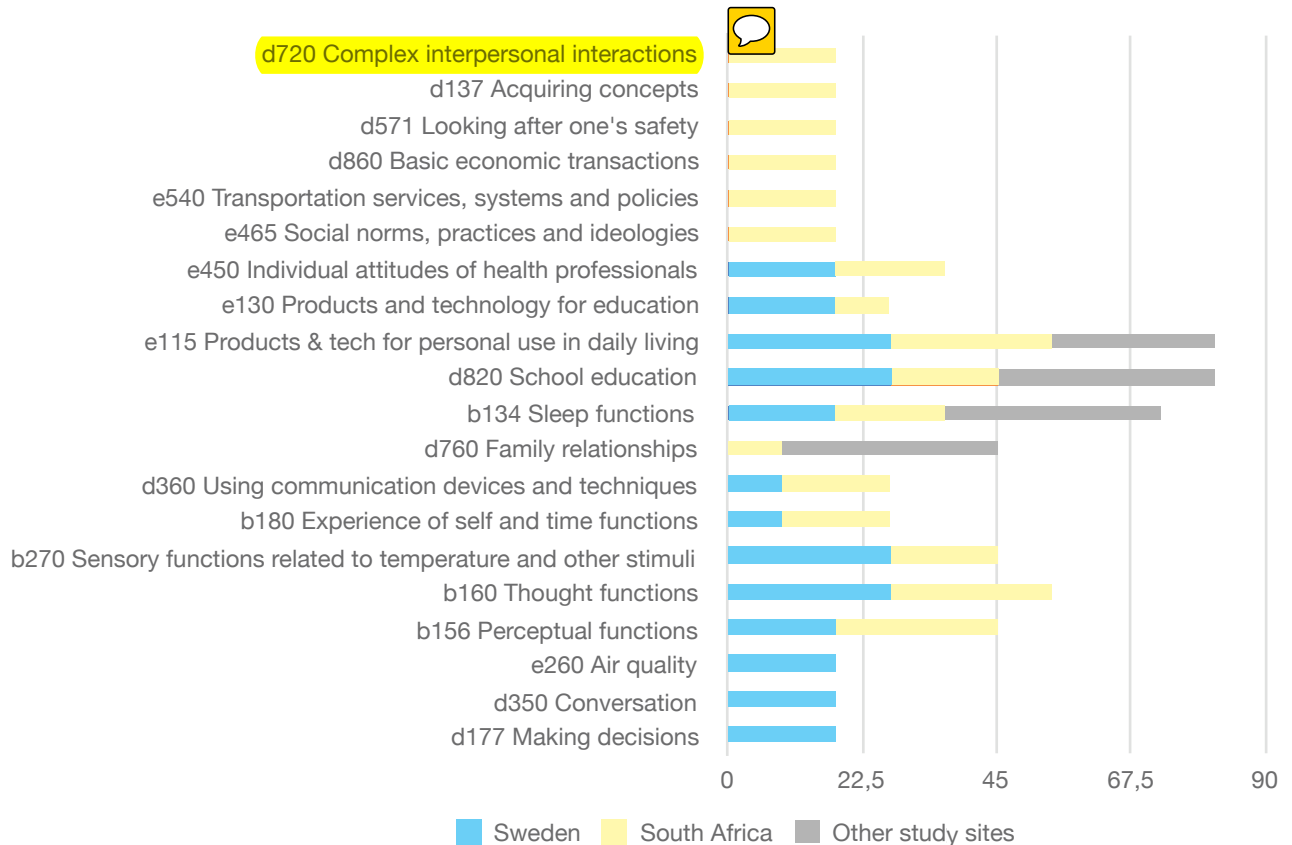


Figure 3.2 Differences in frequency of reporting between South African and/or Sweden and pooled global data study.

Table 3.3 Summary table showing results of the frequency analysis.

Body Functions	Activities and Participation	Environmental Factors
CATEGORIES PRESENT IN 100% OF SOUTH AFRICAN AND SWEDISH GROUPS		
	d230 Carrying out daily routine d540 Dressing d720 Complex Interpersonal Interactions	e310 Immediate family
OBVIOUS DIFFERENCES BETWEEN SOUTH AFRICA AND SWEDEN (SA > S) Mentioned in more South African groups than Swedish groups (SA < S) Mentioned in more Swedish groups than South African groups		
b114 Orientation functions (SA > S) b140 Attention functions (SA < S) b163 Basic cognitive functions (SA > S) b167 Mental functions of language (SA > S) b765 Involuntary movement functions (SA < S) b770 Gait pattern functions (SA < S)	d210 Undertaking a single task (SA < S) d250 Managing one's own behaviour (SA > S) d330 Speaking (SA > S)	e355 Health Professionals (SA > S)
DIFFERENCES BETWEEN SOUTH AFRICA AND/OR SWEDEN COMPARED TO GLOBAL DATA (G > SA, S) Mentioned in all global groups except groups from South African and Sweden (G > SA) Mentioned in all global groups, except in some South African groups (SA, S > G) Mentioned only in groups from South Africa and Sweden and not in any other group from any other country (S > G) Mentioned only in South African data and not in data from any other country around the globe (S > G) Mentioned only in Swedish groups and not in any group from any other country		
b134 sleep functions (G > SA, S) b156 perceptual functions (SA, S > G) b160 thought functions (SA, S > G) b180 experience of self and time functions (SA, S > G) b270 sensory functions related to temperature and other stimuli (SA, S > G)	d137 Acquiring concepts (SA > G) d177 making decisions (S > G) d350 conversation (S > G) d360 using communication devices and techniques (SA, S > G) d571 Looking after one's safety (SA > G) d720 Complex interpersonal interactions (SA > G) d760 family relationships (G > SA, S) d820 school education (G > SA) d860 basic economic transactions (SA > G)	e115 products and technology for personal use in daily living (G > SA) e130 products and technology for education (SA, S > G) e260 air quality (S > G) e450 individual attitudes of health professionals (SA, S > G) e465 social norms, practices and ideologies (SA > G) e540 transportation services, systems and policies (SA > G)

SA = South Africa; S = Sweden; G = Global data set

3.3.3 Content of ICF categories reported in Sweden and South Africa

Only three categories differed qualitatively between South Africa and Sweden. One category emerged from the 100% agreement group (e310 immediate family), one from the obvious differences between South Africa and Sweden group (b140 attention functions) and one from differences between South Africa and/or Sweden and pooled global data (e115 products and technology for personal use in daily living).

Two of the three categories were environmental factors (e115 products and technology for personal use in daily living and e310 immediate family) and one represented body functions (b140 attention functions). Differences in these categories are described below and exemplary meaningful phrases to illustrate differences are given.

3.3.3.1 Immediate family

Swedish participants mentioned 'immediate family' 21 times, all of which was as a facilitator, whereas South African participants mentioned it 52 times as facilitator and eight times as barrier to functioning. Barriers mentioned by South African participants included fathers' negative attitude and/or lack of understanding towards/of their child with ASD, parents not disciplining their children appropriately thus reinforcing challenging behaviour, and lack of support from siblings. Table 3.4 shows exemplary phrases to illustrate these perspectives.

Although 'Immediate family' was identified as a category with qualitative differences between South Africa and Sweden it also contained qualitative similarities in how immediate family members facilitate functioning in their children/family members with ASD. These similarities between South African and Swedish data include parents and other immediate family members (such as grandparents and siblings) help in practical ways. These practical ways include giving medication, adapting the environment to the person with ASD's needs, helping them avoid challenging environments/situations, communicating for them when they are unable to, assisting in developing healthy lifestyle habits such as eating, helping them understand communication and/or others' reactions, home schooling, implementing therapy programmes, helping them understand concepts, helping them manage stress, emotional support, assisting with time management. These practical strategies were often linked by participants to their understanding their child/family member with ASD. Support, love and acceptance of parents, grandparents and siblings were also mentioned in a general, non-specific way. See table 3.4 for exemplary meaningful phrases.

Table 3.4 Summary of meaningful phrases referring to e310 immediate family.

e310 Immediate family	
Sweden	South Africa
Items mentioned as barriers to function	
Fathers' negative attitude and/or lack of understanding	
	☒ The person that brings J down in life is his own father, you know, so that is the person that makes life difficult for J
Parents not disciplining their children appropriately and reinforcing challenging behaviour	
	☒ we (as parents) are afraid of melt down that we are actually creating this obsession
Lack of support from a sibling	
	☒ I mean we have a daughter who is two years younger than him, who basically hates him because of the way he has treated her in the past you know he...
Items mentioned as facilitators of function	
Immediate family members assisting in practical ways	
☒ Mom helps him with his daily life. I get to explain things for him, translate some of the things that are happening in a given situation, like for example why you greet each other when you see the person walking outside.	☒ we have built D's environment based on his interest
General support, love and acceptance from immediate family members	
☒ His grandmother is also very supportive	☒ I think it's having parents like us that's the positive side...Because if we weren't the way we are, it would be very difficult for them. But if we didn't allow them...To be who they are it wouldn't be easy for them

3.3.3.2 Attention functions

'Attention functions' were mentioned six times as a facilitator in Sweden and three times as a barrier in South Africa. Swedish participants mentioned the ability to concentrate/focus for an extended period of time as a positive, where South African participants commented that individuals with ASD are not able to concentrate/focus as expected. Table 3.5 provides meaningful phrases illustrate viewpoints from both countries.

Table 3.5 Summary of meaningful phrases referring to b140 Attention functions

b140 Attention functions	
Sweden	South Africa
☑ One positive aspect is their focus. They can maintain focus for a long period of time.	☒ Yes, concentration is a very big thing...they don't.

3.3.3.3 Products and technology for personal use in daily living

South African participants mentioned 'products and technology for personal use in daily living' a total of four times all of which was as a barrier, whereas Swedish participants mentioned it 14 times as a facilitator and only four times as a barrier.

In both South Africa and Sweden, participants identified several barriers in relation to products and technology for personal use. These included earphones limiting communication, restricted behaviours and/or difficulty dealing with change relating to toys and sensory sensitivity such as sensitivity to certain types of clothing or lights.

Swedish participants mentioned several facilitators in relation to products and technology for personal use. These included computers and iPads helping with communication, socializing and translation of words/language, timers and schedules assisting with daily routine, travel apps helping with travel related issues and board games facilitating socialization. Exemplary meaningful phrases are illustrated in table 3.6.

Table 3.6 Summary of meaningful phrases referring to e115 Products and technology for personal use in daily living.

e115 Products and technology for personal use in daily living	
Sweden	South Africa
☑ The computer helps A. He is interested in computers and he can use it to acquire information about things he does not want to ask questions about. He can just Google the answers on the computer. All his socializing is also done by the computer.	☒ Those earphones are revolting but that has, I mean it also means that he doesn't talk to us as much as he used to which is not necessarily a good thing but those earphones...

3.3.3.4 Additional themes identified through content analysis

Two additional themes emerged from the data using thematic analysis. The two themes will be discussed below.

Health Professionals

ICF categories e355 'health professionals' and e450 'individual attitudes of health professionals' both describe participants' perspectives on health care professionals. Although neither category on its own indicated significant qualitative differences they did differ qualitatively when grouped together.

South African participants mentioned health professionals and individual attitudes of health professionals mostly as a facilitator, where Swedish participants only mentioned it as a barrier.

South African participants mentioned that health professionals understand or make an effort to understand ASD and are helpful. One South African participant mentioned that doctors and nurses do not understand what ASD is. All Swedish meaningful phrases referring to health professionals mentioned lack of understanding. See table 3.7 for a summary of meaningful phrases referring to health professionals.

Table 3.7 Summary of meaningful phrases referring to health professionals.

e355 Health professionals and e450 Individual attitudes of health professionals	
Sweden	South Africa
<input checked="" type="checkbox"/> Health professionals have not been very understanding. I think they should be more accommodating. They have no understanding whatsoever.	<input checked="" type="checkbox"/> His teacher and Doctor S are the best because they have really, really helped me through ...

Sensory processing

Several meaningful concepts over many different categories referred to sensory sensitivity or low registration of sensory information (not noticing sensory information others would). Sensory processing was mentioned only as a barrier to function by participants from both Sweden and South Africa. See table 3.8 for a summary of meaningful phrases referring to sensory processing.

Table 3.8 Summary of meaningful phrases referring to sensory processing.

Sensory Processing	
Sweden	South Africa
<p>☒ He can get these outbursts caused by cheese smell in the air. He can also get outbursts caused by strong scents in the air, even if they are good.</p>	<p>☒ It's difficult in an environment because of their issues with senses...their sensory issues and taking it all in, information, all the sounds and everything at once. Like you say he just wants to shut himself and go away</p>
<p>☒ Fluorescent lamps are not good either, especially considering the fact that these individuals have light sensitivity.</p>	<p>☒ I almost want to say her thermostat is broken. She will put jackets on in summer and short clothes on in summer. It's as of she doesn't feel or she can't comprehend she is warm.</p>

3.4 Discussion

The purpose of the study was to examine the impact of context on functional ability and disability in children with ASD. We focused on parent/caregiver perceptions of functioning by deliberately comparing and contrasting a HIC and a LMIC who participated in the ASD ICF core set development project (Madhi et al. 2017). We aimed to identify and compare the frequency of the most commonly reported functional ICF items identified in the core set study in South Africa and Sweden, and then to examine and compare the content of these categories. We predicted that ICF categories from body functions and body structures would be similar in frequency of reporting, but that environmental factors would be reported more in South Africa than in Sweden. We also predicted that environmental factors would be mostly mentioned as a barrier to functioning in South Africa.

Surprisingly, we found very little support for our hypotheses. We predicted that body structures and body functions would not show differences between HIC and LMIC, given the absolute or universal nature of ASD. However, obvious differences in frequency of reporting between South Africa and Sweden were observed in six out of ten categories relating to body function. ICF body functions include categories describing the core characteristics of ASD and we therefore did not expect to see so many of these items in the 'obvious

differences in frequency of reporting' category. We can reason that some of these core characteristics of ASD were either present in more participants from one country than the other or they were considered more relevant and subsequently reported more in one setting than the other. Given that this study did not measure actual functioning or symptom manifestation we are not able to say which of these two options are more accurate, or whether a combination is perhaps the most relevant. Some of the categories such as 'mental functions of language', 'speaking' and/or 'involuntary movement functions' relate directly to the diagnostic criteria of ASD and it can therefore be speculated that they were also present, but not mentioned in most of the individuals with ASD from the other country. The fact that they were not mentioned in both countries could be due to contextual and/or cultural factors, but might also have to do with the way in which participants answered questions and the items were subsequently coded.


Similarly, categories that were present in all South African and Swedish groups were not from body functions as expected, but mostly from activities and participation (three categories). This result supports previous studies (Coonrod and Stone, 2004; Baker-Ericzén et al., 2005; Guinchat et al., 2012; Azad and Mandell, 2016) suggesting that the functional impact of ASD in activities of daily living are more relevant to families than body functions and often the motivating factor for seeking help.


Our primary prediction was that environmental factors would be more frequently raised as a concern in LMIC settings due to contextual limitations. Interestingly only one environmental factor (health professionals) was identified as different in frequency of reporting. Health professionals were mentioned only in South Africa and not Sweden, and was mentioned as a facilitator rather than a barrier to functioning by South African participants, in contrast to our expectation. This observation suggests that South African participants did not mention environmental factors more than Swedish participants, and that environmental factors can therefore not be assumed to be more relevant/important in a LMIC versus a HIC setting. As shown in chapter 2, most literature from LMIC to date focused on environmental factors. However, results from this study showed that parent/caregivers from a LMIC such as South Africa did not raise environmental factors to a greater extent in relation to their child's functioning compared to parent/caregivers from Sweden.

When comparing South Africa and Swedish data to global pooled data several categories were mentioned only in South Africa and nowhere else in the world. Others were mentioned only in Sweden and nowhere else, and a few were mentioned both in Sweden and South Africa but nowhere else. At first glance several of the categories mentioned only in South Africa such as ‘transportation services and systems’, ‘social norms, practices and ideologies’ and ‘looking after one’s safety’ seemed to be specific to the South African context, but when exploring the content, it was found that only ‘social norms, practices and ideologies’ reflected cultural aspects unique to South Africa such as ancestral worship. The other categories were mentioned relating to the person with ASD’s restricted and repetitive behaviours or inability to judge situations accurately and did not make any direct mention of South African-specific contextual factors such as crime or lack of services. These comments suggest that the way in which family members of participants interact with the environment, rather than the environment or context itself, may be relevant to parent/caregivers.

Similarly, apart from ‘air quality’, categories unique to Sweden were also not obviously specific to the environment (‘conversation’ and ‘making decisions’). When exploring the content of comments under air quality it was found that all participants spoke about sensitivity to an aspect of the environment not perceived by most such as a certain smell. It was thought that these comments could also be classified under the heading of Sensory Processing (not included in the ICF) and was therefore identified as one of the additional themes discussed below.

We also predicted that the content of the themes from body functions would be similar in direction (either facilitator or barrier), but that the content of themes from environmental factors would be different in direction in LMIC and HIC settings. Out of the 34 categories identified as part of the frequency analysis only three were qualitatively different with one additional difference that could be identified when two categories were combined (‘health professionals’ and ‘attitudes of health professionals’). The content of identified categories was more similar than we anticipated between these two very different countries. Differences in content were mostly relating to environmental factors, but these differences were often not in the direction we expected. For example, ‘immediate family’ were mentioned as a facilitator and barrier by South African participants and only as a facilitator by Swedish participants. Another example is ‘health professionals’, reported by most groups in South Africa as a facilitator

to functioning but Swedish groups mentioned ‘attitudes of health professionals’ as a barrier to function. We know that health services and systems are more advanced and better implemented in Sweden than in SA (Langh et al., 2017; Van Schalkwyk, Beyer and de Vries, 2016) but it seems, at least based on data from this study, that South Africans were more satisfied with the limited resources they have access to. In a study examining expectations and responsiveness within healthcare systems Busse and colleagues (World Health Organization, 2013) described that patients with different expectations rated similar experiences differently. It might therefore be that South African participants had lower expectations with regards to availability and access to health professionals and were therefore more satisfied with the services they received, even if these services were limited.  therefore conclude that some environmental factors may be different between cultures, but that these differences are complex, and should not be assumed.

Some of the other categories that differed qualitatively such as ‘products and technology for personal use in daily living’ were not surprising given that the category reflected the fact that Sweden is more advanced technologically than South Africa. 

Additional themes identified included ‘health professionals’ as discussed above and ‘sensory processing’. Sensory processing refers to the neurological process through which sensory input is interpreted and organized to action a motor or behavioural output (Ayres 1971, 1972). Individuals with atypical sensory processing are either more or less sensitive to sensory stimuli than their peers and have difficulty regulating their level of alertness (sensory modulation). It has been reported that individuals with ASD responds differently to sensory stimuli than their typically developing peers (Ornitz et al., 1993; Yeung-Courchesne and Courchesne, 1997; Ermer and Dunn, 1998; Kientz and Dunn, 1997; Watling, Deitz and White, 2001; Cesaroni and Garber, 1991; Tomchek and Dunn, 2007). Several other comments coded under a broad range of other categories described difficulties with sensory processing or regulation. There is however not one ICF category that clearly describes sensory processing which resulted in these comments either being coded under the environmental factor, activity or body functions they relate to. When reading through data it was clear that these comments referred to an additional aspect of functioning not captured in the ICF manual.

3.5 Limitations

We acknowledge a number of limitations of this study. Firstly, the number of participants were relatively small. However, qualitative research typically places a stronger emphasis on data saturation than sample size (Malterud, Siersma and Guassora, 2015). While we recognize this as a limitation and recommend that more studies of this type with larger samples be done, we also recognize that this is the first study, to our knowledge, where perceptions of functioning were compared in this manner. Secondly, even though South Africa has 11 official languages, all South African focus groups were conducted in English. We therefore acknowledge that use of a second language may have influenced participants' ability to express their thoughts clearly. However, one of the inclusion criteria for the overall international study was that participants had to be able to understand and speak English. Thirdly, we observed some differences in response styles between South African and Swedish participants. South African participants were more descriptive, but less direct when answering questions, while Swedish participants gave shorter, more direct answers. It is possible that this was due to the language limitation described above, and that it may have impacted on the way in which a category was coded. However, we used both a South African and Swedish coder for data extraction, which reduced the likelihood that response styles may have biased data analysis. We also acknowledge that the developmental level or severity of ASD of the individuals was not known. It is possible that their developmental level and severity of ASD could have affected the abilities and disabilities reported by parents/caregivers.

3.6 Conclusion

Despite the divergent nature of contexts, few differences were observed in parent/caregiver perspectives about environmental factors relevant to functioning in ASD. Surprisingly, perceptions more frequently differed regarding body functions and activities & participation. The content of perceptions were, with a few exceptions, similar. Our results suggest that the interaction between context and functioning is more complex than we predicted. We recommend that more comparative studies on ASD and functioning should be conducted to gain a better understanding of ASD in different contexts. Our findings suggest that our initial concern about unique perceptions being lost by pooling

data from very diverse countries in the ICF core set development process was unfounded. Results from this study thus support the potential future usefulness of ICF core sets for clinical or other use.

Daley (2002) discussed the fact the individuals experiencing the same contextual factors may attach very different values to it and that the experience of ability/disability is therefor subjective or relative. The findings in our study underlines the importance of the subjective rather than absolute nature of parental experience of context, and of ability and disability in their children with ASD.

CHAPTER 4

Conclusion

4.1 Summary of Findings

In this thesis we set out to examine the relationship between context and functional ability/disability in autism spectrum disorder (ASD). We were particularly interested in parent/caregiver perceptions of functioning since parents/caregivers play such a direct role according to Bronfenbrenner's ecological model (Bronfenbrenner, 1994). In chapter 1 we presented background information on ASD and on the International Classification of Functioning (ICF) biopsychosocial framework for functioning. In chapter 2, we performed a scoping review to determine where in the world research had been conducted to date on parent/caregiver perceptions of functioning in ASD, and to identify the predominant ICF themes raised by parents. In chapter 3 we proceeded to perform a systematic and direct comparison of functional themes raised by parents/caregivers in South Africa and Sweden, by doing a secondary analysis of qualitative data collected for the ICF ASD Core Set Development Project (Mahdi et al., 2017).

Contextual and environmental factors are strong predictors of functional outcomes and an increased understanding of ASD across different settings will improve our ability to meet the needs of individuals living with ASD not only in low- and middle-income countries (LMIC), but also in minority groups in high-income countries (HIC). We predicted that most research findings from LMIC would have focused on contextual or environmental challenges associated with ASD, and that research in HIC would have had a broader range of biopsychosocial themes raised by parents. For the direct comparison of South Africa and Sweden, we predicted that body structures and functions would be equally raised in the two settings, but that environmental factors would predominate in South Africa, as a reflection of the barriers associated with functional outcomes in low-resource environments.

In the scoping review (chapter 2), we identified a total of 33 studies that met inclusion criteria. Of the final 33 studies identified, most were conducted in HIC

(n = 25/33, 76%) as predicted. Only six studies were identified from LMIC (n = 6/33, 18%) and two studies compared perspectives from LMIC and HIC (n = 2/33, 6%).

As hypothesised functional themes from HIC included a range across the ICF biopsychosocial framework with body functions, activities and participation, environmental factors and personal factors all represented. Functional themes from LMIC were more typically focused on environmental and personal factors.

Given that only six of the studies originated from LMIC we should acknowledge that there may have been a research bias that could have resulted in an over-emphasis on environmental factors in LMIC. That is, in low-resource settings, families and researchers may be more conscious of and 'primed' for research on adversity, difficulties with access, and so on. Research topics identified in the scoping review were often predetermined and may therefore have influenced themes that emerged. In order to eliminate this bias we therefore proposed that it may be more accurate to use similar research questions to compare perspectives from LMIC and HIC.

The qualitative phase of the ICF core set development process (Bölte et al., 2014; Mahdi et al., 2017) provided the opportunity to compare parent/caregiver perspectives directly and in a systematic way, given that it asked the same seven questions to participants from six different countries. These questions facilitated conversations around all areas of functioning and created the opportunity for relevant themes from all ICF components to emerge (see chapter 3.3 Data Analysis for details of the methodology).

In chapter 3 we therefore set out to conduct secondary analysis of data collected as part of the qualitative phase of the ICF core set development process. The aim was to explore parent/caregiver perspectives from two of the most divergent countries that participated in the qualitative ICF core set development study by comparing and contrasting the frequency of functional items reported by parents/caregivers between Sweden (HIC) and South Africa (LMIC). We also compared and contrasted the content of functional items identified in these two countries.

Interestingly, our results were almost opposite to what we predicted. We identified some aspects of functional ability and disability to be universally reported by parents/caregivers in South Africa (LMIC) and Sweden (HIC), but

also observed several potentially important differences across ICF categories in frequency of reporting. Environmental factors were more similar in frequency of reporting between Sweden and South Africa than we hypothesized. Immediate family members was the only environmental category mentioned by all Swedish and South African participants, perhaps not surprising considering it has the biggest impact according to Bronfenbrenner's ecological model (Bronfenbrenner, 1994). Surprisingly, perceptions more frequently differed regarding components representing the underlying characteristics of ASD such as body functions. Based on Berry's universal viewpoint as presented in chapter 1, we expected these components to be more similar (Berry et al. 2002).

Qualitative exploration of identified ICF categories revealed that the content was mostly similar, apart from a few categories. The categories that differed qualitatively were predominantly environmental factors as we predicted, but one category from body functions was also included. Differences were often opposite to what we expected. For example, health professionals were mentioned as a facilitator in South Africa and barrier in Sweden.

Our hypotheses assumed that environmental factors would have a bigger and more limiting impact in a LMIC than a HIC. However, when using similar questions in both Sweden and South Africa the results were almost counter-intuitive to what we predicted. This suggests that we should not make assumptions about the influence of context and environmental factors on functioning.

Daley (2002) reasoned that context not only has an impact on functioning, but also has an impact on the value individuals attach to functional themes. That is, what might be considered as important or expected in one context such as a HIC may not necessarily carry the same relevance in another context such as a LMIC. We therefore suggest that objectively, families may live in very different environments in Sweden versus South Africa, and that our objective hypotheses may have driven the expectation of greater concern in LMIC about environmental factors. However, the findings here suggest that the subjective value attributed to context may explain our observations. In Sweden, for instance, families may subjectively have very high expectations of services, health professionals and of air quality, and therefore commented on these as barriers to their children. In South Africa, subjective expectations may have been far lower, resulting in families being grateful for medical support, for instance.

Taking together findings from our work, we therefore suggest that contextual research of parent/caregivers perceptions to date may have been influenced by research/thematic biases, and that direct comparison of families from very different environments highlighted the importance not of absolute objective context but of the subjective value associated with context.

4.2 Limitations of the study

A number of study limitations have already been acknowledged in in chapter 2 and 3. Here we consider some overarching limitations.

4.2.1 We acknowledge the fact that, even though we differentiated between different countries and different functional themes, all interpretations were made based on group findings. There is therefore an intrinsic limitation in the assumption that group findings would be representative of a country or region. It is entirely possible that significant within-country variability exists for all the functional themes examined here. However, given the qualitative nature of the work, there was a deliberate attempt to include a broad range of parents/ caregivers across socio-economic and educational strata in all participating countries, including Sweden and South Africa. We therefore propose that, notwithstanding this limitation, results from this study support the relevance of the newly developed ICF core sets for ASD to diverse groups across the globe.

4.2.2 We also acknowledge that while the ICF provided a useful and widely-used theoretical framework to compare parent/caregiver perceptions, we might have missed some important and relevant themes not captured in the ICF, for instance, sensory processing, which emerged as a theme in our analyses. Future qualitative studies using grounded theory (Glaser and Strauss, 1967; Heath and Cowley, 2004) may therefore identify additional functional themes of importance in LMIC and HIC settings.

4.2.3 The study had a relatively small sample size and participants were recruited from only one city in Sweden and two cities in South Africa. We acknowledge that the work presented here was based on secondary analysis of an international study, where we did not have control over sample recruitment and sample size. Notwithstanding this limitation, it was of great

value to have been able to ensure participation from parents/caregivers across all the WHO regions, and in particular, to have been able to include African voices in this process.

4.3 Future Directions

This was the first cross-cultural comparison of ICF core set studies to our knowledge. There may be value in making similar comparisons in other disorders where core sets have been developed, including ADHD (Bölte et al., 2018).

Given that ASD is highly heterogeneous in nature more comparative studies of this kind may add additional information to enhance our understanding of ASD in LMIC settings and globally. This study highlighted the importance of remaining mindful of context not in an absolute objective sense, but to be sensitive to the perceived subjective environment and resources available to families.

Overall the results from the cross-cultural comparison supports the usefulness of the recently developed ICF core sets for ASD, and the potential value of the short checklists under development for use in clinical practice, service evaluation and research.

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Appendix A: Guide for moderators

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Guide for moderators - steps to be followed during the focus group interview

Introduction (±10 min)

In a first step, you introduce yourself and the group assistant(s), after which all participants introduce themselves. Then you explain the procedure of the session and the objective of the study:

On behalf of my colleagues I would like to welcome you to today's group discussion where you will share your experiences of living with ASD. First, some information concerning the procedure: As mentioned in the information sheet, we will be recording the group discussion. During the recording, my colleagues will be taking notes.

You have agreed to have the group discussion be recorded by signing the consent form. I would like to emphasize that for the transcription your name will be replaced by a code number. To protect your identity the recordings will be destroyed after the evaluation of the data. Do you have any questions so far?

Obtain nonverbal and verbal feedback.

OK! We will now start the recording.

Turn on the recorder.

The group discussion will take between one and one and a half hour. About half way through, we will take a small break.

Now, to the project itself: Having a diagnosis of ASD has a great impact on everyday life. We are interested in your experiences regarding everyday functioning in relation to ASD. You can give us information regarding everyday problems or troubles having to do with ASD. What are the problems and troubles that are especially relevant for those with ASD? To explore this question, we would like to consult you, since you have first-hand experience. You can give us a good impression of what obstacles and problems people with ASD have to face in their everyday lives.

I would like to begin with a short introduction of all participants. My name is [insert your name], I am a [insert your profession] and I work at [insert your clinic/institution]. I will conduct and moderate today's discussion. Please briefly introduce yourself.

Introduction of all participants clockwise.

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Thank you for introducing yourselves. Now I will introduce the questions for the group discussion.

You introduce the discussion about problems associated with ASD using the seven open-ended questions in the topic guide.

During the discussion I will ask you several questions concerning functioning and impairment related to ASD. These questions are intended to be broad and general and they may include anything that you feel is relevant in your life with ASD. Altogether, we will be discussing seven questions in the group. First, I will give you an overview of all seven questions so that you can see which topics we will be discussing. Here are the seven questions.

Read all seven questions out loud.

Regarding the single questions, I am interested in all factors concerning ASD which are especially relevant for you. We will discuss each question one by one. We are interested in all of your personal experiences with ASD. It is important for you to know that there are no correct or incorrect opinions or views. Each of you should feel free to share the problems or troubles you experience. It is also important that within the group, you discuss your views and exchange opinions.

Please respect the following rules of discussion:

- *Each opinion is important and of interest!*
- *Please don't interrupt your partners!*
- *Please don't talk at the same time!*
- *Please deal with the current subject!*
- *Please talk about your own experiences!*

Discussion (±70 min, incl. 10 min break)

You begin the discussion by showing the first question on the screen and reading it out loud. The examples given in the text here can be used as necessary to clarify the question. You can also use the chapters of the ICF-CY (e.g., in Body functions: mental functions, sensory functions, etc.) for inspiration for examples.

Let's begin with the first question:

How does your ASD affect the way your body and your mind works? /How does ASD affect the way the body and the mind of people with ASD works?

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Here we are interested in all factors regarding ASD which you regard as being especially relevant. For example, it could happen that you/they get pain anywhere in your/their body when you/they find yourself/themselves in a situation that is difficult to handle for you/ them. You/they can start to feel warm in your/their body, blush, or get a headache when you/they for example are supposed to go to a party and need to meet a lot of people at the same time. It can also happen that you/they start thinking about that it will be difficult and that you/they get scared of new situations, so that you/they would prefer to avoid them, and there is nothing you/they can do to stop these thoughts and feelings.

You have mentioned several factors regarding the question of what doesn't function on the bodily level. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

In which parts of your body does your ASD give you problems?/In which part of the body does ASD give people with ASD problems?

Here we are interested in all factors regarding ASD which you regard as being especially relevant. For example, does it happen sometimes that you/they feel in your/their body that you/they have ASD? Perhaps when somebody serves you/them food that you/they are not used to. What kind of feelings do you/they get then and where in your/their body do you/they feel it (head, stomach, shoulders, cheeks, heart, legs)?

You have mentioned several aspects regarding the question in which parts of the body can give problems. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

How does your ASD affect the things you can and cannot do in your everyday life?/ How does ASD affect the things people with ASD can and cannot do in their everyday lives?

Here we are interested in all factors regarding ASD which you regard as being especially relevant. It may have happened that you/they had a hard time doing something because of your/their ASD, such as talking in front of class in school, introducing yourself/themselves to strangers or visiting people you/they have never met before.

You have mentioned several aspects regarding the question of what are common problems in daily life. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

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Now to the next question:

What and/or who in the environment where you live and work/go to school make everyday life with ASD difficult for you?/ What and/or who in the environment where they live and work/go to school make everyday life difficult for people with ASD?

Here we are interested in all factors regarding ASD which you regard as being especially relevant. Maybe there are situations related to the environment that are difficult for you/ them, such as a big cafeteria in school with lots of people present at the same time, someone you/they know who talks too fast or is difficult to understand, the way to the gym is long or there is a lot of loud noise in the changing rooms.

You have mentioned several aspects regarding the question of what makes life with ASD more difficult. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

What and/or who in the environment where you live and work/go to school is helpful and supportive in your everyday life with ASD?/What and/or who in the environment where they live and work/go to school is helpful and supportive in the everyday lives of people with ASD?

Here we are interested in all factors regarding ASD which you regard as being especially relevant. Perhaps there is someone or something that can help you/ them in situations that would otherwise be difficult for you/ them to handle. For example a teaching assistant in school who can explain to you/ them what will happen during the day, or your/ their own quiet place to sit or where you/ they can retreat into when there is too much going on around you/ them. Maybe you/ they have your/ their own place in the cafeteria or at home where there is something that can help you/ them feel calm and happy.

You have mentioned several aspects regarding the question of what can be helpful or supportive. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

When you think about yourself and the person you are, what helps you to handle your everyday life with ASD?/When you think about the personal characteristics of individuals with ASD, what helps them to handle their everyday life with ASD?

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Here we are interested in all factors regarding ASD which you regard as being especially relevant. Perhaps you/they are good at logic and therefore learn new things easily. Maybe it is easy for you/them to show when you/they get angry so that others can understand when it is time to leave you/them alone for a while. Maybe you/they are very good at explaining things, which makes it easy to have a conversation.

You have mentioned several factors regarding the question of what is important about you/them and the way you/they handle your/their ASD. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the final question:

What can be the positive sides of living with ASD?

Here we are interested in all factors regarding ASD which you regard as being especially relevant. Perhaps you/they are better at certain things than others who do not have ASD? For example noticing and remembering details, not talking more than is necessary, or being very precise.

You have mentioned several factors that may be positive about having ASD. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Closing (± 10 min)

Finally, you thank all participants for their engagement in the study and briefly give information of what will happen next.

I would like to take this opportunity to thank you for your participation in the group discussion. We were able to collect and discuss several interesting aspects which are relevant to you as a person with ASD/to people with ASD. In the coming time we will be analyzing the information that we collected today and that is collected in the other focus group discussions. Once the analyses are completed we will write a report about our findings that will be published in a scientific journal. If you are interested we will be happy to send the report to you after publication. Please sign up on this list to receive the report.

Show the list and place it where participants can sign up (for example, on their way out of the room).

Finally, we want to show our gratitude for your participation in this focus group by giving you this gift card.


Hand out the gift cards.

Thank you once more for your participation!


Debriefing

After each focus group a debriefing with your group assistants should take place to review the focus group process. We encourage all of you to also share your experiences during the focus groups with the other study sites involved in the study, so that we can all learn from each other.

Appendix B: Visual topic guide



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FOCUS GROUP

FUNCTIONING AND IMPAIRMENT IN ASD

TOPIC GUIDE



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FOCUS GROUP PROGRAM:

- Introduction (± 10 minutes)
- Discussion part 1 (± 30 minutes)
- Short break (± 10 minutes)
- Discussion part 2 (± 30 minutes)
- Closing (± 10 minutes)


INTRODUCTION




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DISCUSSION PART 1

QUESTION 1:


How does your ASD affect the way your body and your mind works?




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Discussion leader:
(Name + additional info)




(add picture)

Assistant(s):
(Name + additional info)



(add picture)

(Name + additional info)



(add picture)

DISCUSSION QUESTIONS:

1. How does your ASD affect the way your body and your mind works?
2. In which parts of your body does your ASD give you problems?
3. How does your ASD affect the things you can and cannot do in your everyday life?
4. What and/or who in the environment where you live and work/go to school make everyday life with ASD difficult for you?
5. What and/or who in the environment where you live and work/go to school is helpful and supportive in your everyday life with ASD?
6. When you think about yourself and the person you are, what helps you to handle your everyday life with ASD?
7. What can be positive sides of living with ASD?



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SHORT BREAK

CONTINUE IN 10 MINUTES


DISCUSSION PART 2




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QUESTION 2:


In which parts of your body does your ASD give you problems?

QUESTION 3:


How does your ASD affect the things you can and cannot do in your everyday life?




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QUESTION 4:


What and/or who in the environment where you live and work/go to school make everyday life with ASD difficult for you?

QUESTION 5:


What and/or who in the environment where you live and work/go to school is helpful and supportive in your everyday life with ASD?




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QUESTION 6:

When you think about yourself and the person you are, what helps you to handle your everyday life with ASD?

QUESTION 7:

What can be positive sides of living with ASD?

Appendix C: Permission to use ICF data



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Stockholms läns
landsting

2017-01-23

Institutionen för kvinnors och barns hälsa
Enhetschef /neuropsykiatri
Professor, PhD
Sven Bölte

TO:

Prof Marc Blockman

Chairman: UCT HREC Committee

Dear Prof Blockman

I am the principal investigator of the Core Set Development Process for ASD and ADHD. I am happy to confirm that Marisa Viljoen has permission to use the data from Sweden and Bloemfontein, as well as other participating countries, for the purposes of her study titled:

"Understanding Autism Spectrum Disorder In Context: A Comparison Of Family Perceptions In A High Income And Low/Middle-Income Country".

Professor Petrus de Vries and Marisa Viljoen have been part of the overall ICF study over the last two years, and are part of the Karolinska ethics approval of this study.

The Karolinska Institute will make the data available once ethical approval has been granted by UCT HREC.

Please do not hesitate to contact me if you need any further information.

Best regards

Sven Bölte
Professor of Child & Adolescent Psychiatric Science
Director of KIND

Adress
Enheten för pediatrik neuropsykiatri
Barn- och ungdomspsykiatriskt
forskningscentrum
Gävlegatan 22 (B, 8 tr)
113 30 STOCKHOLM

Telefon
46 8-514 52701

E-mail
Sven.Bolte@ki.se

Appendix D: Instructions for linking

Instruction for the data analysis(adapted from “User’s guide to perform focus groups and individual interviews - ICF Research Branch)

The data analysis consists of two steps:

- 1) Qualitative analysis to identify meaningful concepts
- 2) Linking the identified concepts to the ICF categories

Figure 1 shows an example of step 1 and step 2 of the data analysis:

Transcription(meaningful concepts)	Step 1: identified concepts	Step 2: linked ICF categories
<i>If you think about your body, what functional problems do you have?</i>		
In former times I went in for sports very often. Now I cannot do it any longer . I even must stop swimming .	Restriction in sports Restriction in swimming	d9201 sports d4554 swimming
<i>If you think about your body, where are your biggest problems?</i>		
toes	toes	s7502 structure of ankle and foot
ankle joints	ankle joints	s75021 ankle joint and joints of foot and toes
knee joints	knee joints	s75011 knee joint
fingers	fingers	s7302 structure of hand

Figure 1. Example for the data analysis process

1. Qualitative data analysis to identify meaningful concepts

The qualitative data analysis will follow the ‘meaning condensation procedure’ in a three-step process. The three steps of the qualitative data analysis should be done separately by two researchers.

Step 1: To become familiar with text

In the first step, both researchers read through the transcribed text of the focus group/individual interview to get an overview.

Step 2: Identification of meaningful concepts

Each of the researchers divides the text into specific units of text, either a few words or a few sentences with a common theme, the so-called meaning units. A meaning unit division does not follow linguistic grammatical rules. Rather, the text is divided where you discern a shift in meaning. Each of the researchers identifies separately the theme that dominates a meaning unit, the so-called meaningful concept, according to standardized rules (see Appendix 1). A meaning unit can contain more than one meaningful concept.

Step 3: Comparison of identified concepts

Afterwards the two researchers compare their retrieved concepts. Disagreement will be resolved by structured discussion. If consensus cannot be reached by discussion a third researcher will make an informed decision to create a final agreed-on version of the identified meaningful concepts.

2. Linking the identified concepts to the ICF

Step1: Linking of the identified concepts to the concepts of the ICF categories

Both researchers separately link the agreed-on concepts to the concepts of the ICF categories according to the linking rules (see Appendix 2;Cieza et al, 2002;Cieza et al, 2005). One concept can be linked to one or more ICF categories, depending on the number of themes contained in the concept.

Step2: Comparison of the linking results

After the linking process, the linking results of both researchers are compared. Disagreement will be resolved by structured discussion. If consensus cannot be reached by discussion a third researcher will make an informed decision to create a final agreed-on version of the linked ICF categories.

Note:

ICF categories are presented at the second-level. If a concept has been linked to a third- or fourth-level ICF category, the corresponding second-level category is reported. This is appropriate, because the lower-level categories share the attributes of the higher-level category.



Appendix 1. Rules for the identification of meaningful concepts

Rule 1: A meaningful concept is a specific unit of text - either a few words or a few sentences - with a common theme. Therefore, a concept division does not follow linguistic grammatical rules. The text is divided where the researcher discerned a shift in meaning. **The basic principle for identifying concepts is to understand the meaning of the text.** To ensure clarity, further elucidations of the concepts will be given in brackets after the identified concept.

Example

Patient A: "I used to go to sports very often. Now I can't anymore. I even had to quit swimming."

Patient B: "Exactly! I also had to quit swimming."

	<u>identifiedmeaningfulconcepts</u>
☺	- restriction in sports - to quit swimming

Rule 2: The interval of time to which the text refers is not considered as a meaningful concept on its own.

Example

„The pain lasts over two hours “

	<u>Identifiedmeaningfulconcepts</u>
☺	- pain
☹	- pain lasts over two hours

Rule 3: Details regarding the extent of a determined problem is to be considered as part of the meaningful concept.

Example

„ I have severe pain in my legs“

	<u>Identifiedmeaningfulconcepts</u>
☺	- severe pain in legs

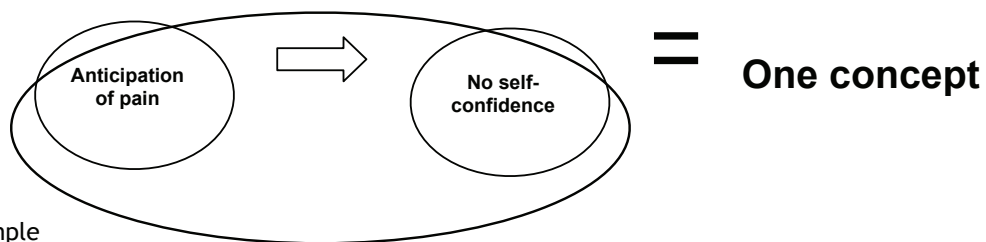
Rule 4: All different single experienced **problems listed** by an individual are to be considered as **independent meaningful concepts**.

Example

„I have serious difficulties getting dressed, putting on my shoes and grooming myself. “

	<u>Identified meaningful concepts</u>
☺	- serious difficulties getting dressed - difficulties putting on one's shoes - serious difficulties grooming oneself
☹	- serious difficulties getting dressed, putting on shoes and grooming oneself

Rule 5: When the relationship between two concepts refers to a **causal relationship**, **one concept will be identified**, namely the cause and the effect:

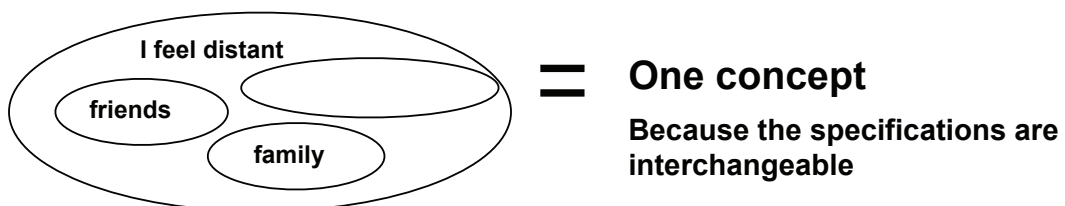


Example

„I have no self confidence because I anticipate the pain.“

	<u>Identified meaningful concepts</u>
☺	- having no self-confidence because of the anticipation of pain
☹	- having no self-confidence - anticipation of pain

Rule 6: Specifications within a concept **will not be considered** as independent **additional concepts**.



Example

“I feel distant from my friends””

	<u>Identified meaningful concepts</u>
☺	- I feel distant from my friends
☹	- to feel distant - friends

Rule 7 Statements of participants about problems or environmental factors, which are not based on own experiences, are not identified as concepts.

Examples

„There is a device for putting on socks, but I don't need it yet. So far, I haven't had any problems putting on my shoes.“

	<u>Identified meaningful concepts</u>
☺	∅
☹	- device for putting on socks - problems putting on shoes

„There is a woman in my self-help group who complains about pain in her ankles.“

	<u>Identified meaningful concepts</u>
☺	∅
☹	pain in ankle

„I once read in a magazine that there is a relation between rheumatism and sclerodermia. There the connective tissue is affected. “

	<u>Identified meaningful concepts</u>
☺	∅
☹	- relation between rheumatism and sclerodermia - connective tissue affected

Rule 8 The absence of a problem is not identified as meaningful concept.

Example

„Do you also have ankle pain? No, I've never had it.“

	<u>Identified meaningful concepts</u>
☺	∅
☹	pain in the ankles

Rule 9 Statements related to problems associated to illnesses other than the condition under discussion will not be identified as concepts.

The comorbidity will be documented as follows: hc - name of illness.

Example

- „I also have diabetes and so I have problems with my eyes. “

	<u>Identified meaningful concepts</u>
☺	- hc - diabetes
☹	- diabetes - problems with eyes

Appendix 2. Rules for the linking of identified meaningful concepts to the ICF

Rule 1 Before you link meaningful concepts to the ICF categories, you should have acquired **good knowledge of the conceptual and taxonomical fundamentals of the ICF**, as well as of the chapters, domains, and categories of the detailed classification, including definitions.

Rule 2 Each meaningful concepts of an answer is linked to the **most precise ICF category**.

Example

Identified concept: problems when walking longer than two kilometers

	ICF category
☺	d4501 Walking long distances
☹	d450 Walking

Rule 3 Do not use the so-called “**other specified**” ICF categories, which are uniquely identified by the final code 8, if the content of a meaningful concept is not explicitly named in the corresponding ICF category.

Example

Identified concept: Problems walking down stairs

	ICF category
☺	d4551 Climbing
☹	d4558 Moving around, other specified

Rule 4 Do not use the so-called “**unspecified**” ICF categories, which are uniquely identified by the final code 9, but use the lower level category which is less specific.

Example

Identified concept: problems in relationship with others

	ICF category
--	--------------

☺	d7 Interpersonal interactions and relationships
☹	d799 Interpersonal interactions and relationships, unspecified

Rule 5 If the information provided by the meaningful concept is **not sufficient** for making a decision about the most precise ICF category it should be linked to, the meaningful concept is assigned **not definable (nd)**.

Example

Identified concept: To have strange feelings when being alone

	ICF category
☺	nd-to have strange feelings when being alone

Special cases for rule 5

a) Meaningful concepts referring to health in general, are assigned **not definable-general health (nd-gh)**, meaningful concepts referring to physical health in general are assigned **not definable-physical health (nd-ph)**, and meaningful concepts referring to mental health in general are assigned **not definable-mental health (nd-mh)**.

Example

Identified concept: Worsening of health

	ICF category
☺	nd-gh
☹	nd

b) Meaningful concepts referring to quality of life in general are assigned **not definable-quality of life (nd-qol)**.

Example

Identified concept: Worsening of quality of life

	ICF category
☺	nd-qol
☹	nd

Rule 6: If the meaningful concept is not contained in the ICF, but is clearly a personal factor as defined in the ICF, the meaningful concept will be assigned to **personal factor (pf)**.

Definition of Personal factors:

Personal factors are the factors which define the person as a unique individual and are not part of her/his condition. To decide whether a determined meaningful concept is a personal factor or not, it is helpful to be aware that from the perspective of the ICF personal factors cannot be impaired, limited or restricted. They can, however, have a positive or negative impact on disability and functioning, i.e. on (impaired) body functions and structures, on (limited) activities, and (restricted) participation. Therefore, if you are not sure whether a meaningful concept is a personal factor or not, ask the following question: Can the [*meaningful concept*] be impaired, restricted or limited? If the answer is no, the meaningful concept is probably a personal factor.

Example

Identified concept: cheerfulperson

	ICF category
☺	pf-cheerfulperson

Rule 7: If the meaningful concept is not contained in the ICF and is clearly not a personal factor, this meaningful concept is assigned **concept not covered by the ICF (nc)**.

Example

Identified concept: loss of leisure time due to the consultations

	ICF category
☺	nc-lossofleisure time due totheconsultations
☹	∅

Rule 8 If the **meaningful concept** is a health condition, the meaningful concept will be assigned to the term **health condition (hc)**.

Example

Identified concept: spinal cord injury

	ICF category
☺	hc-spinal cordinjury

ACTIVITIES & PARTICIPATION COMPONENT

Level 1: Chapter: d5 Self care

Level 2: category: d570 Looking after one's health

Level 3: category: d5702 Maintaining one's health

Level 4: category: d57022 avoiding risks of abuse of drugs or alcohol

Appendix E: Information sheet for focus group participants

Division of Child and Adolescent Psychiatry
Red Cross War Memorial Children's Hospital and
University of Cape Town



46 Sawkins Road, Rondebosch 7700
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Tel. (021) 685 5116 Fax. (021) 689 134

Focus group study about functioning and impairment in persons with ASD

The University of Cape Town together with the Karolinska Institute (Sweden) is carrying out a research project about functioning and impairment in ASD in which we will be conducting focus group interviews with persons with ASD (children, youth and adults) and their relatives (parents, partner and other family members). The focus groups will also include teachers and professional caregivers working closely with persons with ASD. A focus group interview is meant to highlight different experiences around a certain theme, in this case problems and challenges in everyday life for adults with ASD. The focus group interview takes 1-1.5 hours and will consist of 6-8 participants. The interview will be led by a moderator who asks questions about different aspects of functioning and impairment in ASD. See backside for more detailed information about the study.

Background to the project is that the World Health Organization, WHO, has developed a systematic way for describing functioning in different health conditions. The classification is called International Classification of Functioning, Disability and Health, ICF. The aim of this project is to develop an especially adjusted short version of the ICF for persons with ASD. This short version, called Core Set, is intended to create possibilities for improved care and research in ASD. An example could be that in health care a more structured way of describing challenges and possibilities in everyday life for persons with ASD could be developed.

Good to know

- Participation in the study is voluntary and can be ended at any time without further explanation and without any consequences for further contacts with health care. Apart from the time investment participation does not have any known risks or benefits. As a token of our appreciation we will give all who participate in the study a gift card with a value of R100.
- The interview will be audio recorded and information discussed during the interview will be analyzed by researchers. Results will be published in international scientific journals. When the results of the study are presented it will not be possible to identify individual persons.
- None of participant's personal information will be shared with unauthorized people. According to Swedish and European law, however, information can be shared with other researchers and to statistic after special request.
- Participants have the right to view their personal information for free once per year. Should they find any mistakes in their personal information these will be corrected. After 15 years the code key which is coupled to names will be destroyed, after which it will no longer be possible to share any information.

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- The project has been approved by the ethical review board. The Karolinska Institute is the main research body and is responsible for the study. Participants are insured through the patient insurance.

Contact

Are you interested in participating or do you know someone who might be? Contact us if you would like more information or want to sign up to participate.

Responsible for implementation of the study are Marisa Viljoen and James Shelley.
email: VLJMAR010@myuct.ac.za; Telephone: 082 3193492



Focus group study about functioning and impairment in persons with ASD

What?

The focus group interview takes 1-1.5 hours, giving you the possibility to discuss your experiences with functioning and impairment related to ASD in a group of 6-8 persons in your target group. The interview will be led by a moderator according to predetermined questions.

Who?

The following eight target groups will be included in the focus group study:

1. Children (9-12 years old) with ASD
2. Adolescents (13-18 years old) with ASD
3. Adults (18+ years old) with ASD
4. Parents and others closely related to children with ASD (e.g., siblings, grandparents)
5. Parents and others closely related to adolescents with ASD (e.g., siblings, grandparents)
6. Teachers of persons with ASD
7. Other professionals who work closely with persons with ASD (e.g., personal assistants, caregivers in residential care)
8. Representatives from interest organizations for ASD

Where?

The focus group interviews will take place [insert place]

When?

The focus group interviews will take place [insert dates/times]

Contact

Are you interested in participating or do you know someone who might be? Contact us if you would like more information or want to sign up to participate.

Responsible for implementation of the study are Marisa Viljoen and James Shelley.
email: VLJMAR010@myuct.ac.za; Telephone: 082 3193492

Appendix F: Consent form for focus groups - parent/caregivers - English

Division of Child and Adolescent Psychiatry
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46 Sawkins Road, Rondebosch 7700
Tel. (021) 685 4103 Fax. (021) 685 4107
Tel. (021) 685 5116 Fax. (021) 689 134

M.Sc student (and project coordinator): Marisa Viljoen
Principal Investigator: Professor Petrus de Vries

Consent form for parents/caregivers

Development of ICF Core Sets for classification of functioning and impairment in Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD)

Background

The World Health Organisation (WHO) has developed a systematic way for describing functioning in different health conditions. The classification is called International Classification of Functioning, Disability and Health (ICF). The aim of this project is to develop an especially adjusted short version of the ICF for persons with ADHD/ASD. This short version, called Core Set, is intended to create possibilities for improved care and research in ADHD/ASD. An example could be that in health care a better way of describing challenges and possibilities in everyday life for persons with ADHD/ASD could be developed.

As part of the process of developing Core Sets the University of Cape Town will be doing focus group interviews with persons with ADHD/ASD (children, youth and adults) and their relatives (parents, partner and other family members). The focus groups will also include teachers and professional caregivers working closely with persons with ADHD/ASD. The aim of a focus group interview will be to highlight different experiences around problems and challenges in everyday life for adults/children with ADHD/ASD.

What will I have to do?

We would like to invite you to be part of a focus group to discuss your experience around ADHD/ASD. The interview will be led by a moderator who will ask questions about living with ADHD/ASD.

How long will a focus group take?

The focus group interview takes 1-1.5 hours and will consist of 6-8 participants.

What will you do with the information gathered during a group?

The Karolinska Institute in Sweden is the main research body and is responsible for the study. The interview will be audio recorded and information discussed during the interview will be analysed by researchers at the Karolinska Institute. Results will be published in international scientific journals.

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University of Cape Town



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Will the focus groups be confidential?

When the results of the study are presented it will not be possible to identify individual persons. None of participant's personal information will be shared with unauthorised people. According to Swedish and European law, however, information can be shared with other researchers for statistical purposes on special request.

Participants have the right to view their personal information for free once per year. Should they find any mistakes in their personal information these will be corrected. After 15 years the code key which is coupled to names will be destroyed, after which it will no longer be possible to share any information.

How will this focus group benefit me?

Apart from the time investment participation does not have any known risks or benefits. Participation in the study is voluntary and can be ended at any time without further explanation and without any consequences for further contact with the administrators/researchers.

Will I get paid for taking part?

As a token of our appreciation we will give all who participate in the study a gift card with a value of R100. Participant's travel expenses will also be covered up to the value of R100 or equivalent in their local currency.

I hereby confirm that:

- I know that participation in the study is voluntary and that participation can be ended at any time without further explanation and without any consequences for the future health care of my child.
- I have received written and verbal information about the study and have had the possibility to have all my questions about the study answered.
- I am aware that an audio recording of the focus group interview will be made.
- I know that the material will become available to authorized researchers only, and that no information will be shared for purposes other than research.
- I know that individual persons cannot be identified in the results of the study and that all information will be protected against unauthorized use.

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Red Cross War Memorial Children's Hospital and
University of Cape Town



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Tel. (021) 685 5116 Fax. (021) 689 134

I confirm below with my signature that I consent to participation in the study and handling of my personal information as described above.

*Parent's/Caregiver's
Signature*

*Parent's/Caregiver's
name (in print)*

Date

*Parent's/Caregiver's
Signature*

*Parent's/Caregiver's
name (in print)*

Date

Witness' Signature

Witness' name (in print)

Date

Translator's Signature

Translator's name (in print)

Date

Division of Child and Adolescent Psychiatry
Red Cross War Memorial Children's Hospital and
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Tel. (021) 685 5116 Fax. (021) 689 134

I have explained the study to the participant, and in my opinion s/he understands that participation is voluntary and is able to give informed consent.

Researcher's Signature

Researcher's name (in print)

Date

Should you have any questions or queries about the research or your participation, please do not hesitate to contact Marisa Viljoen: (cell) 082 3193 493, (email) VLJMAR010@myuct.ac.za or Professor Petrus de Vries: (telephone) +2721 6854103, (email) petrus.devries@uct.ac.za

Marisa Viljoen
M.Sc student
University of Cape Town
VLJMAR010@myuct.ac.za
(082 3193492)

Prof Petrus de Vries
Sue Struегmann Professor of Child and Division
of Child and Adolescent Psychiatry
University of Cape Town
petrus.devries@uct.ac.za

Participants in this study may contact the **UCT Faculty of Health Sciences Human Research Ethics Committee (HREC)** with any ethical concerns or questions about your welfare as a study participant.
Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory, 7925
sumayah.ariefdien@uct.ac.za (+2721 4066338)

Appendix G: Consent form for focus groups - parent/caregivers - Afrikaans

Afdeling Kinder- en Adollesente Psigiatrie
Rooikruis-kinderhospitaal en die Universiteit van
KaaDstad



Sawkinsweg 46, Rondebosch 7700
Tel. (021) 685 4103 Faks. (021) 685 4107
Tel. (021) 685 5116 Faks. (021) 689 1343

Hoofnavorser: **Professor Petrus de Vries**
M.Sc-student (en projekkoördineerder): **Marisa Viljoen**

Vrywaringsvorm vir ouers/versorgers

Die ontwikkeling van IKF-kernstelle vir die klassifikasie van funksionering en ongeskiktheid in Aandagsgebrekshyperaktiwiteitsindroom (AGHD) en outismespektrumgebrek (OSG)

Agtergrond

Die Wêreldgesondheidsorganisasie (WGO) het 'n sistemiese metode ontwikkel waarop die funksionering in verskillende gesondheidstoestande omskryf kan word. Dié klassifikasie word die Internasionale Klassifikasie van Funksionering, Ongeskiktheid en Gesondheid (IKF) genoem. Die doel van hierdie projek is om 'n spesifiek aangepaste kort weergawe van die IKF vir persone met AGHD en ASD te ontwikkel. Hierdie kort weergawe, naamlik die kernstel, is bedoel om moontlikhede vir verbeterde versorging en navorsing in AGHD/OSG te ontwikkel. 'n Voorbeeld hiervan kan wees dat 'n beter wyse waarop die alledaagse uitdagings en moontlikhede vir persone met AGHD en OGD in gesondheidsorg beskryf word, voorgestel kan word.

As deel van die proses om dié kernstelsel te ontwikkel, sal die Universiteit van Kaapstad fokusgroeponderhoude voer met persone met AGHD/OSG (kinders, jeugdige en volwassenes) en hul familieledede (ouers, lewensmaats en ander gesinslede). Die fokusgroepe sal ook onderwysers en professionele versorgers insluit wat daaglik met persone met AGHD/OSG werk. Die doel van 'n fokusgroeponderhoud sal wees om die verskillende ondervindings rondom probleme en uitdagings in die alledaagse lewe van volwassenes/kinders met AGHD/OSG te beklemtoon.

Wat staan my te doen?

Ons wil jou graag nooi om deel te wees van 'n fokusgroep om jou ervaring van AGHD/OSG te bespreek. Die onderhoud sal gelei word deur 'n moderator wat vrae sal vra.

Hoe lank sal die fokusgroep duur?

Die fokusgroeponderhoud sal 1-1,5 uur duur en uit 6-8 deelnemers bestaan

Wat gebeur met die inligting wat tydens die onderhoud ingesamel word?

Die Karolinska-instituut in Swede is die hoofliggaam vir navorsing en is daarom verantwoordelik vir die studie. Die onderhoud sal opgeneem word en inligting wat deur die onderhoud bespreek word sal deur navorsers aan die Karolinska-instituut ontleed word. Resultate sal in internasionale wetenskaplike joernale gepubliseer word.

Sal die fokusgroepe vertroulik wees?

Wanneer die resultate van die studie voorgelê word, sal dit nie moontlik wees om die individuele persone te identifiseer nie. Die deelnemers se persoonlike inligting sal met ongemagtigde persone gedeel word nie. Volgens Sweedse en Europese wetgewing kan inligting wel op spesiale aanvraag vir statistieke doeleindes met ander navorsers gedeel word.

Deelnemers het die reg om hul persoonlike inligting een keer per jaar gratis te besigtig. Indien daar enige foute in hul persoonlike inligting is, sal dit reggestel word. Ná 15 jaar sal die kodesleutel wat aan name gekoppel is vernietig word en daarna sal dit nie langer moontlik wees om enige inligting te deel nie.

Hoe sal die fokusgroepe my beoordeel?

Behalwe vir die tyd wat aan die deelname verbonde is, is daar nie enige bestaande risiko's of voordele nie. Deelname aan die studie is vrywillig en kan enige tyd sonder verdere verduideliking en sonder enige nagevolge en verdere kontak met die administrateurs/navorsers gestaak word.

Sal ek betaal word vir my deelname?

As 'n teken van ons waardering sal ons 'n geskenkbewys ter waarde van R100 aan alle deelnemers in die studie gee.

Hiermee verklaar ek dat:

- Ek weet dat deelname aan die studie vrywillig is en dat deelname enige tyd gestaak kan word sonder verdere verduideliking en sonder enige nagevolge vir die toekomstige gesondheidsorg vir my kind.
- Ek weet dat deelname aan die studie vrywillig is en dat deelname enige tyd gestaak kan word sonder verdere verduideliking en sonder enige nagevolge vir die toekomstige gesondheidsorg vir my.
- Ek geskrewe en verbale inligting oor die studie ontvang het en die geleentheid gehad het om al my vrae oor die studie te laat beantwoord.
- Ek bewus is dat 'n klankopname van die fokusgroeponderhoud gemaak sal word.
- Ek weet dat die materiaal slegs aan gemagtigde navorsers beskikbaar gestel sal word en dat geen inligting vir doeleindes anders as navorsing gedeel sal word nie.
- Ek weet dat individuele persone nie deur die resultate van die studie geïdentifiseer kan word nie en dat inligting teen ongemagtigde gebruik beskerm sal word.

Ouer/Versorger se handtekening

*Ouer/Versorger
se naam (in drukskrif)*

Datum

*Ouer/Versorger se handtekening
(in drukskrif)*

Ouer/Versorger se naam

Datum

Getuiene se handtekening

Getuiene se naam (in drukskrif)

Datum

Vertaler se handtekening

Vertaler se naam (in drukskrif)

Datum

Ek het die studie aan die deelnemer verduidelik en na my mening verstaan hy/sy dat deelname vrywillig is en dat hy/sy ingeligte toestemming gee.

Navorsers se handtekening

Navorsers se naam (in drukskrif)

Datum

Sou jy enige navrae oor die navorsing of deelname hê, moenie huiwer om Marisa Viljoen: (sel) 082 3193 493, (e-pos) VLJMAR010@myuct.ac.za of Professor Petrus de Vries: (telefoon) +2721 6854103, (e-pos) petrus.devries@uct.ac.za te kontak nie.

Marisa Viljoen
M.Sc-student
Afdeling Kinder en Adollesente Psigiatrie
Universiteit van Kaapstad
VLJMAR010@myuct.ac.za (082 3193492)

Prof Petrus de Vries
Sue Struegmann Professor in Kinder- en
Adollesente Psigiatrie
Universiteit van Kaapstad
petrus.devries@uct.ac.za

Deelnemers aan hierdie studie kan die Fakulteit Gesondheidswetenskappe Menslike Navorsing-etiekskomitee kontak met enige etiese kwessies of vrae oor jou welstand as deelnemer aan hierdie studie.

Kamer E52-24 Ou Hoofgebou
Groote Schuur-hospitaal
Observatory, 7925
sumayah.ariefdien@uct.ac.za (+2721 4066338)

Appendix H: Consent form for focus groups - parent/caregivers – isiXhosa

Division of Child and Adolescent Psychiatry
Red Cross War Memorial Children's Hospital and
University of Cape Town



46 Sawkins Road, Rondebosch 7700
Tel. (021) 685 4103 Fax. (021) 685 4107
Tel. (021) 685 5116 Fax. (021) 689 134

Inzululwazi yesisifundo:

Professor Petrus de Vries

MSC Umfundi (umphathi wezophando):

Marisa Vlojen

Incazelo yothathi nxaxheba kunye nonompilo okanye umntu omjongileyo.

Development of ICF Core Sets functioning and impairment in Attention Dificity hyperactivity disorder ADHD and autism spectrum Disorder ASD

Imvelaphi

I World Health Organisation iphuhlise ngezinye indlela ngokucacisa izinto ngendlela ezahlukengayo ngokwezempilo. Umohluko walonto wabizwa ukuba yi International Classification of Functioning Disability and Health (ICF). Ezonanjongo zoluphando kukuphuhlisa eyona indlela yokunciphisa yokwenza mfutshane izinto kwi ICF kubantu abane ADHD/ASD. Lendlela imfutshane ibizwa ukuba yi Core Sets, injongo kukwenza eyona ndlela yokuphuhlisa nesiphatho nakunye nezophando kwi ADHD/ASD. Umzekelo ingaba yindlela entle yokucacisa izinto esidibana nazo ngamaxesha amaninzi obomi kubantu abane ADHD/ASD kungabakho uphuhliso.

Ekubeni isaqhubeka ikhula i Core Sets, i University of Cape Town izobe ineqela eliyi Focus Group ezakubuza imibuzo kubantu abane ADHD/ASD (kubantwana nabadala) (nakwizihlobo nasebazalini nakwezinye izizalwana). I Focus Group izofuna kubekhona otishala ne ngcaphephe nonompilo basebenzisane kunye kubantu abane ADHD/ASD. Ezona njongo kukubabuza ezonanto zahlukeneyo nolwazi nengxakiabathi bajongane nazo ebomini maxesha onke kubantu abadala nabantwana abane ADHD/ASD.

Kufuneka ndenzentoni?

Sifuna ukuba ubeyinxalenye yeli qela elibizwa yi Focus group sizoxoxa malunga

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nolwazi lwakho le ADHD/ASD.
Imibuzo izobe ibuzwa ngeyokuphila ne ADHD/ASD.

Izothatha ixesha elingakanani i Focus Group?

I Focus Group izothatha umzuzu omnye okanye onomzuzwana.

Izakuthiwani incazelo yam ekubeni sihleli?

I Karolinka Institution in Sweden lelona qela lijongene nesisifundo.
Ingxoxo izakushicilelwa ,baxoxe ngencazelo yakho abaphandi ba Karolinska
Insitute ngabo abazokwenza iziqgibo.
Iziphumo zizakukhutshwa jikelele kwintatheli ezihambisana nezempilo.

Kuzobe kuyimfihlo kweli qela le Focus Group?

Ekubeni ziphumile iziphumo zesisifundo kuzoboniswa ngazo,azizobonakala
ukuba zisuka kubanina .

Ezinye incazelo zabathathi nxaxheba zizakuba selungelweni zikwazi ukuchazela
abantu zibancede zifundise.Ngokomthetho wase Swedish nase European
ezincazelo zingabaluncedo kubanye abantu nabaphandi ngenjongo
zokuncedisana.Umthathinxaxheba unelungelo lokujonga incazelo yakhe kanye
ngonyaka,ukuba kuye kwafunyanwa impazamo kwincazelo bazazilungisa.

Emveni kweminyaka elishumi elinehlanu inombolo namagama azocinywa kuzo
kwazi abanye bangazifumani incazelo zakho.

Ndizakuyifumana inzuzo kule Focus Group?

Ukuthatha inxaxheba kwesisifundo kukuzinikela kwaye ungayeka nanina ufuna
naxeshaphi ungadanga wayokuchazela abaphandi.

Ndizakubhatalwa ngokuthatha ingxaxheba?

Kwisivumelwano sethu umthathinxaxheba uzofumana i gift Card eyenza i R100.

Ndiyavuma:

Division of Child and Adolescent Psychiatry

Red Cross War Memorial Children's Hospital and
University of Cape Town



46 Sawkins Road, Rondebosch 7700
Tel. (021) 685 4103 Fax. (021) 685 4107
Tel. (021) 685 5116 Fax. (021) 689 134

- Ndiyayazi ukuthatha inxaxheba kwesisifundo kukuzinikela futhi ndingayeka nxeshaliphi ndifuna ndingakhange ndiyokuchazela abaphathi.
- Ndicaciselekile ngempendule nangemibuzo kwesisifundo ndaphenduleka. Ndiyayazi ukuba kuzakubakho ushicilelo.
- Ndiyayazi ukuba izakuba sisixhobo kubaphandi esizothi sincede kuchazelwe abanye abantu ngencazelo yam.
- Ndiyayazi ukuba incazelo yam izakuba yimfihlelo ayizokwaziwa nangubanina neziphumo zam zikhuselekile kwezizifundo zizakuba selungcinweni.

Umzali Tyikitya (parent signiture)

Umzali Igama (name)

Umhla (date)

Iqgina Tyikitya (witness signiture)

Iqgina Igama (witness name)

Umhla

Ndimcacisele umthathi nxaxheba ngesisifundo kwaye ngokubona kwam ucaciselekile i ndoda/mfazi uyayazi ukuthatha ingxaxheba kwezizifundo kukuzinikela futhi uyavuma nokusinika incazelo yakhe.

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University of Cape Town



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Tel. (021) 685 4103 Fax. (021) 685 4107
Tel. (021) 685 5116 Fax. (021) 689 134

Umphandi Tyikitya

Umphandi Igama

Igama

*Ukuba unemibuzo okanye kukho into ongayiqondiyo kwezi zifundo noluphando
nceda ungoyiki ukuqhagamishelana no Marisa Viljoen inombolo (0823193493)
email VLMR010@myuct.ac.za .*

Marisa Viljoen
M.Sc Student
Division of Child and Adolescent Psychiatry
University of Cape Town
VLMR010myuct.ac.za (0823193492)

Prof Petrus de Vries
Sue Sruegmen Professor of a Child Adolescent Psychiatry
University of Cape Town
Petrus.devriesuct.ac.za

Umthathi nxaxheba angaqhagamishelana ne UCT Faculty of Health Science Human Research
Ethic Committee (HREC) Nantonina engakwehlela okanye oxhalabe ngayo unemibuzo
nangesiphatho sakhe kwesisifundo.
Igumbi e52-24 Kwibilide Elidalalase
Groote Schuur kwisibhedlele
Observatory
7925
sumaya.ariendien uctac.za(0214066338)

Appendix I: Client Record Form (CRF) parent/caregivers

Division of Child and Adolescent Psychiatry
Red Cross War Memorial Children's Hospital and
University of Cape Town



46 Sawkins Road, Rondebosch 7700
Tel. (021) 685 4103 Fax. (021) 685 4107
Tel. (021) 685 5116 Fax. (021) 689 1343

Dear participant,

Thank you for taking the time to participate in our study. By taking part in our focus group you will help us to get a clearer picture of what everyday life with ASD looks like, and what kind of challenges persons with ADHD meet in their everyday activities.

Before the focus group meeting takes place, we would like to ask you to fill in this short questionnaire concerning general information about yourself and the person(s) with ASD you are related to. This will help us to get an overview of our participant group.

Please follow these instructions when filling in the questionnaire:

- Use a ball point pen to fill in the questionnaire
- For each question (except question 1 and 4) mark the box for the answer that applies to you with an X
- If you accidentally mark the wrong box, draw a single line through it and mark the correct box with an X

Example:

Yes No

- For each question mark only one box

We kindly ask you to fill in this questionnaire and to bring it with you to the focus group meeting. We look forward to meeting you there!

Kind regards,

The project team

Professor Petrus J de Vries

Marisa Viljoen



46 Sawkins Road, Rondebosch 7700
Tel. (021) 685 4103 Fax. (021) 685 4107
Tel. (021) 685 5116 Fax. (021) 689 1343

The following questions concern you

1. Date of birth (yyyy-mm-dd).

				-			-		
--	--	--	--	---	--	--	---	--	--

2. Gender

- Female
- Male

3. Your relation to the person/persons with ASD

- Parent/caregiver
- Teacher
- Partner
- Personal caregiver
- Other, please specify: _____

The following questions concern the person/group of people with ASD you are related to

4. What is the age of the person/group of people with ASD? In case of a group of people, please give the age range.



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 Tel. (021) 685 4103 Fax. (021) 685 4107
 Tel. (021) 685 5116 Fax. (021) 689 1343

5. What subtype of ASD does the person/group of people with ASD have? In case of a group of people, please indicate all relevant subtypes.

- Asperger's syndrome
- Classic autism
- I don't know
- Other, please specify: _____

6. Please indicate by marking one of the boxes below how good you think the general health of the person/group of people with ASD is. Mark more to the left if you think their health is good, mark more to the right if you think their health is poor. In case of a group of people, please give an indication that best represents the group as a whole.

--	--	--	--	--	--	--	--	--	--	--

Excellent

Poor

7. Please indicate by marking one of the boxes below how much of a problem you think the everyday functioning of the person/group of people with ASD is. Mark more to the left if you think it is no problem, mark more to the right if you think it is more of a problem. In case of a group of people, please give an indication that best represents the group as a whole.

--	--	--	--	--	--	--	--	--	--	--

No problem

Complete

8. Make an X next to the 3 things that you think makes your life the most difficult:

- Not having enough money
- Having to travel far to get to places you need to go. For example shops, hospital, work)
- Not having a job
- Autism Spectrum Disorder (ASD)
- The place and area in which you you live
- Safety - not feeling safe in the area where you live and/or work
- Difficult relationships
- Other: _____;

FOR PARENTS ONLY:

9. Highest level of education (of parents)

- Primary school
- High school
- Vocational education
- Higher education (for example university, technicon)
- None
- Other, please specify: _____

10. Work status (of parents)

- Student
- Supported employment
- Paid employment
- Self-employment
- Unpaid employment (volunteer work, etc.)
- Homemaker

- None

11. Living situation

- Living with immediate family members (only parents and children living together)
- Living with extended family (grandparents, cousins)
- Other, please specify: _____

12. Type of home/dwelling

- Brick house with water and sanitation (toilet)
- Brick house without water and sanitation (toilet)
- Informal settlement with water and sanitation
- Informal settlement without water and sanitation
- Other, please specify: _____

13. Accessibility of basic educational services (schools)

- Basic educational services less than an hour's travel away
- Basic educational services more than an hour's travel away

14. Accessibility of basic medical services (clinics, hospitals)

- Basic medical services less than an hour's travel away
- Basic medical services more than an hour's travel away

15. Total household income per annum (in local currency)

16. What type of treatment does your child receive for ASD?

- Medication, please specify: _____
- Therapy, please specify: _____
- None
- I don't know
- Other, please specify: _____

17. How many hours per month does you spend on activities to help your child's ASD? Examples of activities include therapy, doctor visits, collecting medication?

- 0-1 hours
- 2-5 hours
- 5-10 hours
- more than 10 hours
- other, please specify: _____

Appendix K: Ethical approval Karolinska (Swedish)



BESLUT

Bilaga

Dnr 2014/53-31/2

Sökande: Karolinska Institutet
Behörig företrädare: Sven Bölte, Professor
Projekt: Utveckling av ICF Core Sets för klassifikation av funktionshinder vid ADHD och autismspektrumtillstånd
Forskare som genomför projektet: Sven Bölte

Vid sammanträde den 19 februari 2014 beslutade nämnden att sökanden skulle komplettera ärendet enligt följande:

Deltagarinformationen ska kompletteras med information och samtycke för åldrarna 15-18 år.

Nämnden lämnade över åt den vetenskaplige sekreteraren att avgöra ärendet sedan kompletteringen gjorts.

BESLUT

Nämnden godkänner forskningen.

På nämndens vägnar


Pär Spårén
Vetenskaplig sekreterare

2014-03-10

Postadress
FE 289
171 77 STOCKHOLM

Besöksadress
Nobels väg 9
Solna

Telefon
08-524 864 00 (vx)

Fax
08-524 866 99

E-post
kansli@stockholm.epn.se

Hemsida
www.epn.se

Ordförande

Christian Groth

Ledamöter med vetenskaplig kompetens

Pär Sparén vetenskaplig sekreterare (*medicinsk epidemiologi*) deltog ej i 2014/119 pga. jäv

Aniko Bartfai (*klinisk neuropsykologi*) ej närvarande (*skriftliga föredragningar*)

Kristian Borg (*neurologi*)

Mats Eriksson (*endokrinologi*)

Yvonne Forsell (*psykiatri, geriatrik*)

Kristina Johnell (*geriatrik och läkemedelsepidemiologi*)

Agneta Karsten (*odontologi*)

Matthias Löhr (*onkologi*)

Anna Nilsson (*pediatrik, infektion och immunologi*) ej närvarande (*skriftliga föredragningar*)

Thomas Sejersen (*neuropediatrik*)

Ledamöter som företräder allmänna intressen

Katarina Bergvall

Kemo Ceesay

Charlotte Helmersson

Ingmar Wallén

Administrativ sekreterare

Jenny Karte

§ 1 Ordföranden förklarar sammanträdet öppnat.

§ 2 Administrativ sekreterare anmäler att den vetenskaplige sekreteraren sedan föregående möte den 22 januari fattat beslut i ett antal ärenden som avser ändring av godkännande.

§ 3 Ansökningar om etisk granskning av forskningsprojekt, se **Bilaga**.

§ 4 Med stöd av 27 §, tredje stycket, etikprövningslagen beslutas att lämna över till ordföranden och vetenskapliga sekreteraren att ompröva beslut enligt 27 § förvaltningslagen.


§ 5 Ordföranden meddelar att nästa sammanträde i avdelning 2 äger rum **onsdagen den 19 mars**.

§ 6 Ordföranden förklarar mötet avslutat.



Christian Groth
Ordförande

Kristian Borg
Vetenskaplig sekreterare
(Ärende 2014/119)



Pär Sparén
Vetenskaplig sekreterare

Appendix L: Ethical approval Karolinska (English)



EPN - Stockholm

Regional ethical review board

DECISION

Applicant: Karolinska Institutet

Authorized representative: Sven Bölte, Professor

Project: Development of ICF Core Sets for classification of functioning and impairment in ADHD and ASD

Researcher responsible for the project: Sven Bölte

During the meeting on 19 February 2014 the committee decided that the applicant should complete the matter according to the following:

Information for participants should be completed with information and consent for ages 15-18 years.

The committee left it to the scientific secretary to decide on the matter as soon as the supplement was made.

DECISION

The committee approves the research.

On behalf of the board

Pär Sparén

Scientific secretary

Appendix M: Ethical Approval UCT



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

05 November 2015

HREC REF: 506/2015

Prof P de Vries
Child & Adolescent Psychiatry
46 Sawkins Road
Rondebosch

Dear Prof de Vries

PROJECT TITLE: DEVELOPMENT OF ICF CORE SETS FOR CLASSIFICATION OF FUNCTIONING AND IMPAIRMENT IN ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) AND AUTISM SPECTRUM DISORDERS (ASD)

Thank you for your response letter addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th November 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC reference no in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

Hrec/ref: 506/2015

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix N: Ethical Approval Red Cross Hospital



Western Cape
Government

Health

Dr AS Booysen
Manager: Medical Services
Email: Tony.Booyesen@Westerncape.gov.za
Tel: +27 21 658 5788 fax: +27 21 658 5166

Prof PJ De Vries
Red Cross War Memorial Children's Hospital

Dear Prof PJ De Vries

APPROVAL OF RESEARCH

PROJECT TITLE: DEVELOPMENT OF ICF CORE SETS FOR CLASSIFICATION OF FUNCTIONING AND IMPAIRMENT IN ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) AND AUTISM SPECTRUM DISORDERS (ASD)

It is a pleasure to inform you that approval is hereby granted to conduct the above-mentioned study at Red Cross War Memorial Children's Hospital.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Booyesen', written over a horizontal line.

Dr AS Booysen
Manager: Medical Services
Date: 29.02.16

Appendix O: Dr Griessel Letter of Permission to Use Data



17/01/2017

TO WHOM IT MAY CONCERN

Masters degree: Understanding autism spectrum disorder in context: A comparison of family perceptions in a high income and a low and middle income country.

Candidate: Marisa Viljoen

I am a member of the executive committee of Autism South Africa and a developmental Paediatrician. I was approached by Prof P de Vries of the division of Child and Adolescent Psychiatry to identify children and young adults in my practice who fulfilled the criteria for the diagnosis of an autism spectrum disorder and who would be willing to attend the focus groups in Bloemfontein on Saturday 5 December 2015.

This was done as part of an ICF core set development project (HREC 506/2015).

I hereby give permission to Ms Viljoen to use the data obtained in Bloemfontein for the master's degree.

Yours sincerely

DR DJ GRIESSEL MBChB MMed

HEAD: DEVELOPMENTAL PAEDIATRICS

UNIVERSITAS HOSPITAL

C:Candidate Marisa Viljoen Jan 2017 Dr Griessel.doc

