

# Parent education and training for autism spectrum disorder: evaluating the evidence for implementation in low- resource environments

By

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1. Dawson-Squibb, J.J., Davids, E.L., & de Vries, P.J. (in press). **Scoping the evidence for EarlyBird and EarlyBird Plus, two UK-developed parent education and training programmes for autism spectrum disorder.** *Autism*

2. Dawson-Squibb, J., & de Vries, P.J. **Developing an evaluation framework for parent education & training in Autism Spectrum Disorder: results of a multi-stakeholder process.** (Submitted to *BMC Implementation Science*)

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## ABSTRACT

The World Health Organization has recognised Autism Spectrum Disorder (ASD) as a public health concern and have recommended access to appropriate assessment and interventions. Psychoeducation and parent support soon after diagnosis are considered global best practice. Parent Education & Training (PET) programmes provide education, skills and support to parents. Despite the high need for PET there has been limited research in this field and few programmes are available, particularly in low- and middle-income countries (LMIC). This project aimed to 1) evaluate the evidence-base for a UK-developed PET (EarlyBird/EarlyBird Plus); 2) evaluate the evidence-base for a broader range of PET; 3) generate a framework for evaluating global PET programmes; 4) conduct a comparative feasibility study of two PET programmes in South Africa.

The EarlyBird/EarlyBird Plus scoping review identified a low level of evidence for the efficacy of the PET, and showed that relatively little implementation science examination of the programmes had been performed to date. Review of a broader range of PET showed very similar findings, suggesting that the field of PET (rather than any specific intervention) was still relatively immature. We proceeded to use an implementation science and participatory approach to generate a multi-stakeholder evaluation framework for PET in future studies. A mixed-methods quasi-experimental design was then used for a comparative feasibility study of two PET in a low-resource South African setting. In the feasibility study parents/carers found both programmes to be acceptable and adaptable for a South African context. Limited efficacy-testing showed positive outcomes for parents, children and families. Application of the Evaluation Framework proved to be a useful structural technique to identify the strengths and weaknesses of PET across the implementation themes of outcomes, processes & procedures, and implementation landscape. Taken together, our results highlighted the relative infancy of this important field of ASD research and identified the need for multi-site, randomized controlled trials of PET, particularly in low-resource settings. In addition, results underlined the importance not only of efficacy of programmes, but of a range of implementation-related factors, that are crucial to ensure sustainable and scalable PET in real-life settings around the globe.

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# STYLE, ABBREVIATION AND KEY TERMS

A note on spelling and style convention: UK English spelling has been used throughout this thesis. I have used Harvard referencing throughout the thesis for the same reason, and compiled all references at the end of this thesis.

## ABBREVIATIONS

<b>ASD</b>	–	Autism Spectrum Disorder
<b>WHO</b>	–	World Health Organization
<b>LMIC</b>	–	Low- and Middle-Income Country
<b>PET</b>	–	Parent Education & Training

## KEY TERMS

Autism Spectrum Disorder

Implementation science

Parent Education & Training

Evaluation Framework

Low-resource environments

Comparative feasibility

# Chapter 1

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## Introduction

### 1.1 Introduction to the thesis

The overarching theme of this thesis was to explore the evidence-base for post-diagnostic education and training programmes to parents who have children with Autism Spectrum Disorder (ASD). The deliberate ‘lens’ used here was to focus on the needs of families in low-resource environments, such as typically seen in Low- and Middle-Income Countries (LMIC). With the simple clinical question of ‘what is the best programme for my setting, and how do I determine that?’, the thesis started with an evaluation of the evidence-base for a specific set of programmes from the UK called EarlyBird & EarlyBird Plus (Chapter 2), before performing a broader review of parent education and training programmes (Chapter 3). We discovered that there were no universally adopted evaluation frameworks for such programmes, and therefore proceeded in chapter 4 to develop a framework using a multi-stakeholder consensus strategy. The Evaluation Framework was used in chapter 5 as a guide for a comparative feasibility study of two parent education and training programmes – one a widely-used UK-developed programme EarlyBird & EarlyBird Plus, and the other a locally developed programme, Autism Cares.

In spite of the importance of post-diagnostic education and training, the thesis identified a relatively underdeveloped literature with fairly low-level evidence of outcomes, and little evidence on other aspects of key importance for implementation. We concluded in chapter 6 that the ‘evidence-base’ for programme selection needs to include evaluation of the ‘processes & procedures’ and the ‘implementation landscape’, in addition to traditional ‘outcomes’.

## **1.2 Introduction to Autism Spectrum Disorder (ASD)**

Autism Spectrum Disorder (ASD) are acknowledged by the World Health Organization (WHO) as a major global public health challenge (WHO, 2013; Abubakar et al., 2016; de Vries, 2016; Franz et al., 2017; Guler et al., 2017). The majority of individuals with ASD live in LMIC and receive very limited services from health, education and social care systems (de Vries, 2016; Tekola et al., 2016; Tilahun et al., 2016; Franz et al., 2017; Guler et al., 2017). One of the logical first steps after a diagnosis of ASD anywhere in the world, is the provision of post-diagnostic psychoeducation to parents and carers to help them understand the meaning of ASD, the facts and figures about ASD, what they can do to support their own child's learning and development, and how to prepare themselves for their journey with a developmental disability.

ASD is characterised by persistent deficits in social communication and social interaction across multiple contexts in combination with restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). It is classified as a neurodevelopmental disorder and symptoms are typically present from early stages of development and continue to unfold and change over the course of the person's life (NICE guidelines, 2013; NIH, 2017). To meet DSM-5 criteria, observed symptoms must cause clinically significant impairment in social, occupational or other important areas of functioning.

The disorder has a prevalence rate in the region of 1% (Elsabbagh et al., 2012; Hansen, Schendel, Parner, 2015; Christensen et al., 2016). However, the majority of prevalence studies have been performed in High-Income Countries (HIC) rather than LMIC. South Africa, the location of this thesis has, for instance, not had any ASD prevalence studies due to a number of reasons, including lack of funding, lack of suitable screening and diagnostic tools, and lack of expertise (Malcolm-Smith et al., 2013; Durkin et al., 2015; de Vries, 2016; Franz et al., 2017). Based on comparisons of other global studies, there is no reason to presume estimates would differ dramatically in South Africa or other LMIC. The relative absence of ASD diagnoses in current health and educational records suggests that ASD is likely to be significantly under-

identified and that the majority of individuals with ASD are not receiving appropriate services (Abubakar et al., 2016; de Vries, 2016; Franz et al., 2017).

Apart from affecting the individuals who have ASD, these pervasive and often severe disabilities have also been associated with a range of stressors for parents and caregivers. These include increased parenting stress, decreased parenting efficacy and an increase in mental and physical health problems compared to parents of children with other developmental disorders (Khanna et al., 2011; Karst & Van Hecke, 2012; Eapen & Guan, 2016; Vasilopoulou & Nisbet, 2016). Additional strains of financial and time pressures have been reported, as well as higher rates of divorce and lower overall family well-being (Karst & Van Hecke, 2012; Hoefman et al., 2014). Caring for a child with ASD has been shown across a range of cultures and countries to impact significantly on parent/carers Quality of Life (QOL) (Eapen & Guan, 2016). This lower overall QOL is poorer compared to parents/carers of typically developing children or those with other disabilities (Poza, Sarria, & Brioso, 2014; Eapen & Guan, 2016). These negative impacts can in turn reciprocally affect the child with ASD (Karst & Van Hecke, 2012).

### **1.3 Parent/carer-focused intervention for ASD**

In literature relating to ASD the term intervention includes a wide range of approaches including child-based intervention, parent-led intervention, parent skills training and parent education/psychoeducation or combinations thereof. Parents and carers play a critical role in ensuring optimal child developmental outcomes in general and particularly in ASD. And as such the potential of parent mediated interventions – where parents are trained to work directly with their child – has become a significant focus in intervention research (Irwin, Siddiqi & Hertzman, 2007; Kasari, Lawton & Shih, 2014; Nevill, Lecavalier & Stratis, 2016).

There is increasing evidence that the functioning and quality of life of a person with ASD is highly dependent on family and parental factors such as parental knowledge, stress, and family support (Eapen & Guan, 2016; Vasilopoulou & Nisbet, 2016). Parental factors can, for

instance, have a direct impact on adherence to interventions and to their efficacy (Remington et al., 2007; Grindle et al., 2009). Grindle et al. (2009), for example, have explored the experience of parents attending Early Intensive Behavioural Intervention (EIBI) programmes over two years and emphasised the importance of directly addressing the parents' emotional well-being on the programme. They concluded that EIBI courses should provide more support for families on home programmes, emphasising that such focused family support could have a positive impact on outcomes in the child with ASD. For these, amongst many reasons, parent education and support is a key component of ASD interventions (McConachie & Diggle, 2007; Steiner et al., 2012; Cutress & Muncer, 2014; Lauritsen, 2013).

To our knowledge, despite the clear and high need, there has been relatively limited research on post-diagnostic education and training programmes to parents/carers particularly in low-resource environments.

#### **1.4 Parent Education & Training: a comment on taxonomy**

Bearss and colleagues (2015) provided a useful framework and taxonomy for ASD interventions involving parents/carers. They suggested a distinction between 'Parent Support' programmes, where the parent /carer is the direct focus and the child is an indirect beneficiary, in contrast to 'Parent/Carer-Mediated Interventions' where parents/carers are coached to work directly with their children and the child is therefore the direct beneficiary of the intervention. The focus of the programmes in this thesis will be predominantly 'Parent Support' in nature given that the focus is on education work with parents/carers, and the children are not direct participants in the programmes. However, some so-called parent support programmes also incorporate home visits that may include video-guided coaching and training. In terms of the Bearss et al (2015) taxonomy, the many programmes are therefore hybrids between 'Parent Support' and 'Parent-mediated Interventions'. For this reason, we will use a placeholder term 'Parent Education & Training' (PET) when referring to such programmes. We define PET as the passing on of information or skills to parents using a range of modalities (didactic, role-play, discussions, video-guidance) in a context where parents/carers and trained facilitators are the direct participants. By implication, the

emphasis is on transferring knowledge to parents and the priority participants are parents /carers and not the parent-child dyad.

## **1.5 Implementation science, community based participatory research, and feasibility studies**

Damschroder et al. (2009) described implementation science as a method of enquiry designed to support investigators in determining whether interventions or approaches can be implemented in real-world settings. These settings, they suggest, may differ in many ways from the original settings (Damschroder et al., 2009).

Bammer (2005) proposed that implementation science to be built on three pillars. 1) systems thinking, which look at the whole and its relationship to its parts; 2) participatory methods, which emphasise that every stakeholder has a contribution to make in both understanding and, where relevant, decision making; and 3) the exchange, implementation and management of knowledge, which involves recognising that there are many forms of knowledge and ways of knowing which provides enhanced methods for accessing knowledge. This last pillar particularly notes that both volume and diversity of knowledge can be regarded as barriers.

Rather than replacing traditional disciplinary and specialist perspectives, implementation science complements them and collaboration is regarded as central to how it operates. As described by Bammer (2005), implementation science can contribute to these partnerships in a number of ways, including:

- Bridging between research and practice;
- Expanding on ways of taking uncertainty into account and of managing less than perfect outcomes;
- Expanding ways of encompassing change in both research and practice;

- Enhancing appreciation of how to improve collaborative processes in research, e.g., ensuring that appropriate researchers and sectoral representatives are included, that their world views are made explicit, that their interests are accommodated, that different strengths are harnessed, that communication mechanisms are strong, and that conflicts are appropriately mediated.

As outlined by Bowen et al. (2009), a feasibility study may be indicated for a number of reasons including when:

- Prior studies of a specific intervention technique in a specific population were not guided by researchers familiar with the target population and in partnership with the targeted communities;
- Previous interventions had positive outcomes but in different settings than the one of interest;
- Community partnerships need to be established, increased, or sustained.

With the guidelines above and given the limited research on intervention for parents of children with ASD in South Africa, a feasibility study for ASD PET programmes seemed appropriate. Bowen et al. (2009) described that smaller studies which use mixed methods may produce more innovative feasibility studies. For the purposes of this thesis we used the feasibility-related terminology as outlined by Bowen and colleagues (2009) as shown in Table 1.1. Only the four main terms relevant to the focus of this thesis were defined, i.e. 'Feasibility studies', 'acceptability', 'adaption' and 'limited efficacy testing'.

**Table 1.1. Summary of terms relating to feasibility studies (Bowen et al., 2009)**

Feasibility studies	These studies can address different sections of the eight general areas are, acceptability, demand, integration, implementation, practicality, expansion, adaptation and limited efficacy testing.
Acceptability	This common target of research focuses on how the intended recipients - both targeted individuals and those involved in implementing programmes - react to the intervention.
Adaptation	This focuses on altering programme content or procedures to be appropriate in a different or new situation. Emphasis is on detailing the particular modifications that are made to accommodate the context or requirements of a different format, media, or population.
Limited efficacy testing	Many feasibility studies are intended to test an intervention in a limited way. These tests are often conducted with a convenience sample, using intermediate rather than final outcomes, and with shorter follow-up periods, or with limited statistical power

## **1.6 Aims of the thesis**

The thesis had four main aims:

1. To evaluate the current evidence-base for EarlyBird and EarlyBird Plus, two widely used PET for ASD, with an emphasis on efficacy (outcomes) and other aspects of feasibility.

2. To evaluate the current evidence-base for all PET programmes for ASD outside the USA, with emphasis on the range of PET, the research done in the area and the focus given to feasibility.
3. To generate an evaluation framework for ASD PET programmes, incorporating multi-stakeholder participation.
4. To perform a comparative feasibility study of two contrasting PET programmes in a LMIC, including the use of the Evaluation Framework.

## 1.7 Hypotheses

This study had two overarching hypotheses.

First, with regards to the existing evidence-base for PET, we predicted to find a good evidence-base for PET programmes in high-income countries, but with limited emphasis on feasibility of programmes.

Second with regard to data generated as part of this thesis we predicted to find high acceptability and evidence of positive outcomes of both programmes, but expected significant need for cultural adaptation of the UK-developed EarlyBird and EarlyBird Plus programmes. We did not make any specific *a priori* hypotheses about the ASD PET Evaluation Framework as part of the thesis.

# Chapter 2

---

## **Scoping the evidence for EarlyBird and EarlyBird Plus, two UK-developed Parent Education and Training programmes for Autism Spectrum Disorder.**

Dawson-Squibb, J.J., Davids, E.L., & de Vries, P.J. (in press). *Autism*.

### **2.1 Introduction**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with the core features of persistent impairment in reciprocal social communication and social interaction, and the presence of restricted and stereotypical behaviours (APA, 2013). In recent studies, the reported population prevalence of ASD was in the region of 1% (APA, 2013; Blumberg et al., 2013; Christensen et al., 2016). In addition to its high prevalence, ASD also account for substantial health loss across the lifespan as measured by disability adjusted life years (Baxter et al, 2015).

To mitigate against such significant potential loss, the need for post-diagnostic intervention and support has been highlighted as part of best practice (Lauritsen, 2013; NICE Guidelines, 2011). The fundamental aim in contemporary ASD interventions is to target the core deficits associated with ASD using a range of naturalistic developmental behavioural interventions, including early intensive behavioural interventions (Schreibman et al., 2015). It is, however, also recognised that the functioning and quality of life of a person with ASD is also highly dependent on family and parental factors such as parental knowledge, stress, and family support. There is evidence that parental factors can have a direct impact on adherence to interventions and to their efficacy (Remington et al., 2007; Grindle et al., 2009). For example, Grindle et al. (2009) explored the experience of parents attending Early Intensive Behavioural Intervention (EIBI) programmes over the course of two years and highlighted the need to “directly address the emotional well-being of parents of children on EIBI programs”. They

concluded that EIBI courses in particular should provide more support for families on home programmes, emphasising that such targeted family support may have a positive impact on the outcomes for children with ASD (Grindle et al., 2009). For these reasons parent education and support is a key component of ASD interventions (Lauritsen, 2013).

Bearss and colleagues (2015) provided a useful framework and taxonomy for ASD interventions involving parents/carers. They suggested a distinction between 'Parent Support' programmes, where the parent/carer is the direct focus and the child is an indirect beneficiary, in contrast to 'Parent/Carer-Mediated Interventions' where parents/carers are coached to work directly with their children and the child is therefore the direct beneficiary of the intervention. The programmes reviewed here are predominantly 'Parent Support' in nature given that the focus is on education work with parents/carers, and children are not direct participants in the programmes. However, the EarlyBird/EarlyBird Plus (EB/EBP) programmes do also include some home visits, where video guided coaching and training is included. In terms of the Bearss et al. (2015) taxonomy, the programmes are therefore hybrids between 'Parent Support' and 'Parent-Mediated Interventions'. For this reason, we will use the term Parent Education & Training (PET) when referring to the EB/EBP and similar programmes. We define PET as the passing on of information or skills to parents using a range of modalities (didactic, role-play, discussions, video guidance) in a context where parents/carers and trained facilitators are the direct participants. By implication the emphasis is on knowledge transfer to parents and the priority participants are parents/carers and not the parent-child dyad.

Research on PET for ASD is relatively limited and few studies have evaluated any PET as stand-alone interventions, despite the fact that access to quality information is one of the most requested needs by parents of children with a recent diagnosis of ASD (Whitaker, 2002; Hamilton, 2008; Bearss et al., 2015). In a very helpful review, Schultz, Schmidt & Stichter (2011) summarised the literature on PET for ASD published between 1987 and 2007. Previous reviews of this area had all demonstrated the benefits of parent education (Brookman-Frazee et al., 2006; McConachie & Diggle, 2007) and indicated that PET can increase parental knowledge and skills in managing behaviour and teaching children communication and social skills (Charlop-Christy & Carpenter, 2000; Solomon, Necheles, Ferch & Bruckman, 2007).

Additional benefits of reducing parental stress and increasing parental sense of competence were also highlighted. The Schultz, Schmidt & Stitche (2011) review sought to build on these findings by determining the key characteristics of PET programmes along with how they were evaluated and what outcomes were reported on. A limitation acknowledged in their otherwise comprehensive review, was the fact that only articles from the USA were included. The authors stated that “without question, parent education in other countries would contribute to our understanding of the research in this area” (Schultz, Schmidt & Stitche, p.102).

Schultz and colleagues (2011) identified 30 articles that met their inclusion criteria. Interestingly, the majority of programmes used a one-on-one approach (80%), although positive outcomes were reported regardless of format (1:1 or group-based). They commented that, whilst one-on-one approaches may provide individualised learning opportunities, a group-based approach could be both more cost-effective and have the potential to reach larger groups of parents. They recommended that further research should seek to isolate the variables associated with effective group-based education. Farmer and Reupert (2013) also commented that group programmes have the added value of promoting mutual support and opportunities to share personal experiences with other parents.

The evaluation of ASD PET programmes have typically focused on a range of outcomes such as increased parental knowledge, enhanced competence in advocating for the child, decreased parental stress and a reduced sense of isolation (Tonge et al., 2006; Farmer & Reupert, 2013). Parental stress, in particular, has shown marked reductions in response to parent education (Koegel, Bimbela & Schreibman, 1996).

Schultz, Schmidt & Stitche (2011) sought, as part of their systematic review, to determine the manner in which the ASD PET programmes were evaluated. They noted that the majority of the research used single-case designs (70%) followed by pre- and post-test designs. To this extent, they suggested that the current literature reflected the relative infancy of ASD PET literature. They further recommended that future researchers include detailed information about programme components and to extend the field, promoted replication.

Initial feasibility research is considered an important component of programme evaluation in this area, particularly given the infancy of the ASD specific literature. Feasibility in academic literature, and particularly in the field of health interventions, covers a broad range of constructs (Brooke-Sumner, Lund & Petersen, 2016). Bowen et al. (2009) suggested that feasibility, using its broadest definition, can be divided into eight subgroupings, viz. acceptability (e.g. how participants perceive an intervention); demand (is the intervention taken up); implementation (can it be delivered); practicality (despite constraints of time and resources); adaptation; integration; expansion and limited efficacy testing. Progress on how best to assess feasibility, particularly in mental health services in High Income Countries (HIC), has improved over time (Bird et al., 2014; Brooke-Sumner, Lund & Petersen, 2016).

### **2.1.1 EarlyBird and EarlyBird Plus: two group-based PET programmes**

The EarlyBird (EB) programme, designed to assist parents/carers of preschool children who had recently been diagnosed with ASD, is an example of a PET programme. The programme, based on a number of theoretical models, was developed as a 12-week group-based training by the United Kingdom National Autistic Society (NAS) in 1997. Its broad aims were 1) to support parents immediately after diagnosis, 2) to empower parents and encourage a positive perception of their child's ASD, and 3) to help parents establish 'good practice'. 'Good practice' was defined by the developers as the parents' ability to understand ASD and to manage the effects of ASD on the child's development (Shields, 2000). The EarlyBird Plus (EBP) programme, for parents of schoolgoing children under the age of nine years, was developed in 2003 and has broadly similar aims to EarlyBird. Apart from age the other difference in EBP is that families can also invite one additional professional who regularly works with the child to attend the course with the parents/carers. A maximum of six families at a time can attend the EarlyBird programmes.

Each EarlyBird group session lasts for 2 ½ hours and is closely structured, following the protocol given in the training manual. Following the attendance of a pre-programme information meeting describing what EarlyBird is, parents then agree to participate in the programme and a home visit is conducted. A summary of the structure that then follows is presented in Table 2.1.

**Table 1.1. Summary of EarlyBird programme structure**

<b>Name</b>	<b>Theme</b>	<b>Brief description</b>
Group Session 1	Autism	<ul style="list-style-type: none"> <li>• Introduction to ASD</li> <li>• What is EarlyBird</li> <li>• How people with ASD experience the world</li> </ul>
Group Session 2	ASD and communication	<ul style="list-style-type: none"> <li>• How people with Autism make sense of the world</li> <li>• Communication development</li> <li>• Communication in people with ASD</li> </ul>
Group Session 3	Working with your child	<ul style="list-style-type: none"> <li>• Useful techniques to help learning</li> <li>• Playing People Games</li> </ul>
Home Visit A	People Games	<ul style="list-style-type: none"> <li>• Practice a parent-child interaction game</li> </ul>
Group Session 4	Visual structure and support	<ul style="list-style-type: none"> <li>• Report back/sharing people games</li> <li>• Supporting communication</li> <li>• Visual support and structure</li> </ul>
Group Session 5	Preventing problems and developing play routines	<ul style="list-style-type: none"> <li>• Hyperlexia and use of books</li> <li>• Play and children with ASD</li> <li>• Daily and play routines</li> </ul>
Home Visit B	Play routines	<ul style="list-style-type: none"> <li>• Practice a routine at home</li> </ul>
Group Session 6	Understanding behaviour	<ul style="list-style-type: none"> <li>• Sharing play routines</li> <li>• Using the iceberg to analyse behaviour</li> <li>• The STAR approach (Settings, Triggers, Actions, Results)</li> </ul>

Group Session 7	Managing behaviour (A)	<ul style="list-style-type: none"> <li>• Repetitive behaviour, special interests and obsessions</li> <li>• Temper tantrums and aggression</li> <li>• Fears and phobias</li> </ul>
Home Visit C	Something to celebrate	<ul style="list-style-type: none"> <li>• Parents' choice of activity</li> <li>• Encourage identification of goals</li> </ul>
Group Session 8	Managing behaviour (B)	<ul style="list-style-type: none"> <li>• Eating</li> <li>• Sleeping</li> <li>• Toileting and hygiene</li> <li>• Summary and celebration</li> </ul>
Follow-up Session either group or home visit (3months later)	Review	<ul style="list-style-type: none"> <li>• Celebrate progress of adults/child over the past 3 months</li> <li>• Collect follow-up questionnaires</li> </ul>

EB/EBP was specifically developed by the NAS, the leading non-profit organisation for ASD in the UK, to assist parents directly after diagnosis. It is widely implemented in the UK National Health Service (NHS) as a first-line post-diagnostic intervention for ASD, after which more individualised interventions can be accessed. To date, over 27,000 families in the UK and 13 other countries have participated in EB/EBP programmes. The programmes are run by licenced trainers who have undergone a 3-day training session provided by the NAS. There are currently 3,657 EB/EBP trainers registered with the NAS who are able to deliver the programme.

Since its development, the vast majority of research on the EarlyBird and EarlyBird Plus programmes has reported positive outcomes and suggests that it meets the intended aims (e.g. Birkin et al., 2008; Hardy, 1999; Shields & Simpson, 2004). Parental responses detailed in the research have indicated that the programmes have empowered parents, reduced stress levels and facilitated positive perceptions of their child's ASD.

Despite the wide scale implementation of EB/EBP there has not been any comprehensive or independent review of the evidence-base for the EarlyBird programmes. We therefore set out to summarise the landscape of EB/EBP research by evaluating the context for the programmes; the study populations; design; outcome measures used and whether the focus was on parental perception, parental change or on child change. In addition, we specifically set out to examine which other aspects of feasibility had been evaluated.

## **2.2 Methods**

The current review employed a scoping review methodology. Scoping reviews have been defined as processes of mapping the existing literature or evidence-base (Armstrong et al., 2011) with the aim of describing the extent and nature of the programmes, summarising existing literature about the programmes as well as identifying potential research gaps in the body of knowledge to inform future research (Arksey & O'Malley, 2005; O'Flaherty & Phillips, 2015).

### *2.2.1 Search procedure*

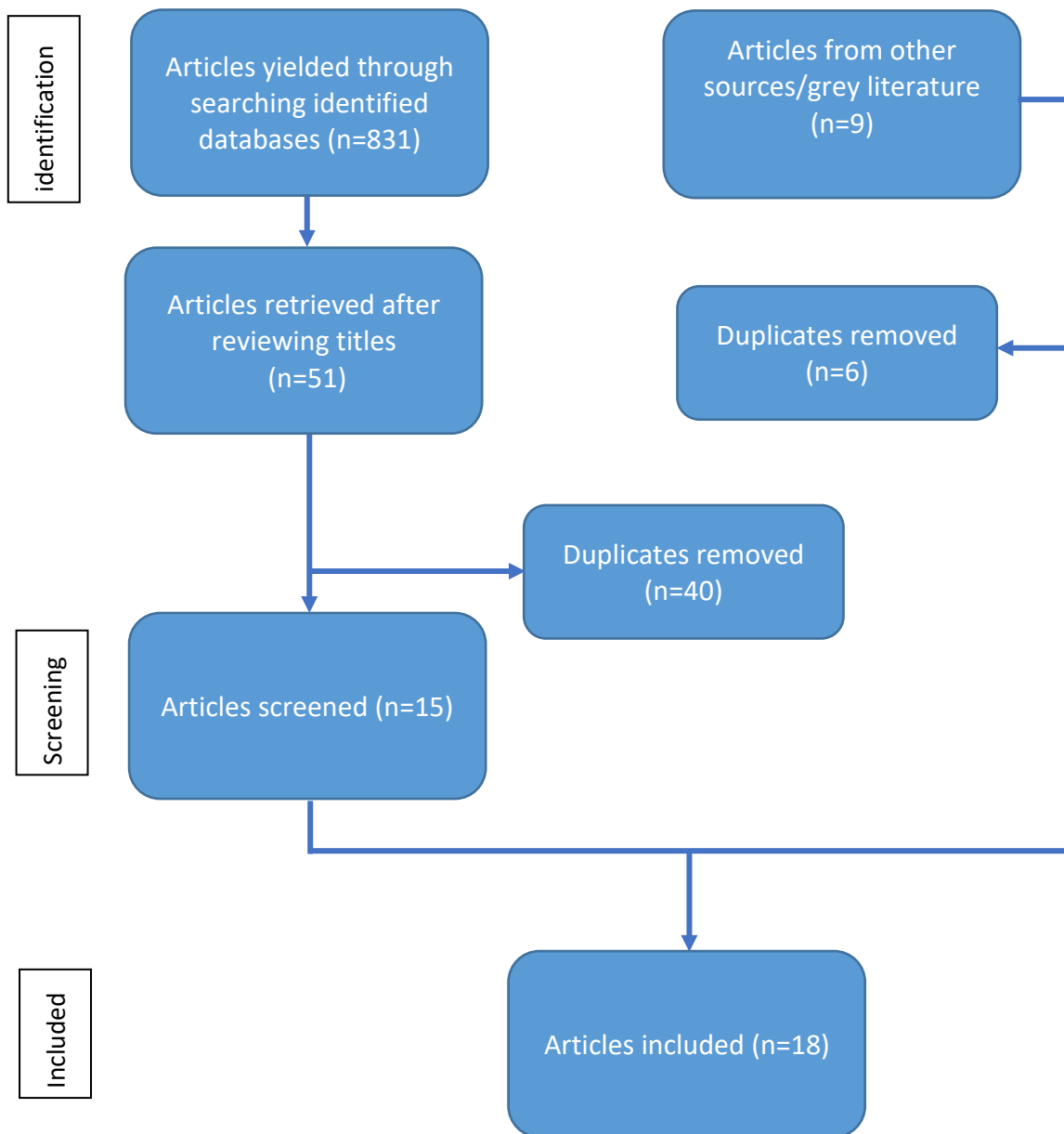
A search during the months of February to June 2016 was conducted including relevant articles up to June 2016 and using the following databases and journals: EBSCOhost (which included: Africa Wide, Medline, CINAHL, Academic Search Premier, ERIC, Health Source: Nursing/Academic Edition, PsycArticles, PsycInfo, SocIndex), Sabinet, SAGE Journals, Directory of Open Access Journals (DOAJ), BioMed Central, Scopus and Science Direct. The databases were searched for articles that have used the National Autistic Society's EarlyBird and EarlyBird Plus programmes with no date restrictions. The review protocol was registered and approved on the International Prospective Register of Systematic Reviews (PROSPERO) (CRD42016039111).

The searches were conducted by two reviewers (JJDS; ELD) independently, using the following keywords with Boolean logic and operators: 'EarlyBird'; 'EarlyBird Plus'; 'Autism'; 'Parent Skills Training'; 'Skills Training'; 'Psychoeducation'; 'Parent Support'; 'Parenting Programmes' and 'Parent Training'. The two reviewers (JJDS; ELD) independently screened titles and

abstracts of studies using the inclusion criteria. Where consensus during the searches and screening was not reached between the two reviewers, the senior author (PJdV) was involved to help reach a consensus. In the searches and screening of the review there was, however, no need to employ a consensus strategy. The inclusion criteria for studies to be considered within the review were, that the research study had to 1) be published in any available language, 2) with no date restrictions, 3) be a study of either EarlyBird or EarlyBird Plus and could be 4) any study design, given the aim to provide a comprehensive overview of all studies using the programmes since its development, and 5) use a quantitative, qualitative, or mixed methodology.

The initial screening of the selected databases yielded 831 studies of which 780 did not meet the inclusion criteria (See Figure 2.1) leaving 51 studies meeting the inclusion criteria. These 51 studies were then screened for any duplicates and 15 studies remained after the removal of duplicates generated across the different databases. Searching the reference lists of the 15 retrieved studies by hand, nine additional studies (including journal articles and dissertations) were retrieved.

When the additional studies were included in the pooled sample of retrieved studies, an additional screening was conducted to remove any new duplicates that might have emerged. Six new duplicates emerged in the retrieved sample of studies, leaving the total number of included studies in the review at 18. The 18 studies then underwent data extraction by the two independent reviewers. Data extraction took place using a data extraction sheet that gathered data pertaining to: author details; study aims and purpose; study sample and setting; study design; outcome variables measured or examined in the study; main study findings as well as major strengths and limitations in the study. An additional data extraction process was followed to examine and extract data about the feasibility of the studies taking into consideration elements of feasibility as outlined by Bowen et al. (2009). These elements included acceptability; delivery; implementation; practicality; adoption; integration and expansion, in addition to efficacy testing.



**Figure 2.1. PRISMA Flow Diagram**

## 2.3 Results

### *2.3.1 Overview of reviewed studies*

The final sample of 18 studies included in the review consisted of 13 studies of the EarlyBird parenting programme; two using the EarlyBird Plus programme and three using both the EarlyBird and EarlyBird Plus programmes. Geographically, 16 of the studies were conducted in the United Kingdom and two in New Zealand. The publications included four quantitative, five qualitative, six mixed-method and three factual descriptions of the programmes without any quantitative or qualitative data. The full summary of results is detailed in Table 2.2.

**Table 2.2: Summary of all studies on EarlyBird and EarlyBird Plus**

First author (year)	Purpose of study / paper	Sample & Setting	Study Design & Intervention	Outcome variables with measures	Findings	Major Strengths & Limitations	Parental Views	Parental Changes	Child Changes	Feasibility
<b>FACTUAL DESCRIPTIONS (WITHOUT DATA)</b>										
Shields (1999)	Descriptive paper about EarlyBird.	N/A United Kingdom	N/A	N/A	N/A	Good description of EarlyBird intervention. Did not provide details regarding the evaluation of the efficacy of intervention (such as RCT).	Y	N	N	AC
Shields (2000)	Descriptive paper about EarlyBird.	N/A United Kingdom	N/A	N/A	N/A	Describes what the EarlyBird intervention is well, but does not provide any details regarding the evaluation of efficacy of intervention using a RCT for example.	Y	N	N	AC
Shields (2001)	Descriptive paper about EarlyBird.	N/A United Kingdom	N/A	N/A	N/A	Provides insight into the EarlyBird intervention but does not provide details regarding the efficacy of the intervention.	N	N	N	AC, P, IM, AD, IN, EX, ET
<b>QUANTITATIVE RESEARCH DESIGNS</b>										
Shields (2004)	To evaluate the EarlyBird intervention, to establish differences	119 families of children with ASD. 36 attended intervention at EarlyBird Centre	Non-randomised Control Design: Repeated	Parental stress: Parenting Stress Index – Long Form Number of words used during parent-child	No significant changes during pre-treatment phase of delayed-	The strength of this study is the use of a control as part of this non-experimental /	Y	Y	Y	AC, IM, IN, EX, ET

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<p>between the control and intervention period, and to compare differences between EarlyBird and Licensed User sites</p>	<p>(24 were delayed-treatment controls) and 83 at Licensed User sites.</p>	<p>measures / delayed-treatment design</p>	<p>interaction: Video word count</p> <p>Child behaviour: Childhood Autism Rating Scale</p> <p>Child development: Vineland Adaptive Behaviour Scale –Long Form</p>	<p>treatment controls.</p> <p>For total sample significant improvements in parental stress, communication and video word count post-intervention.</p>	<p>non-randomised control design. Study failed to make use of randomisation in allocation of control and experimental groups.</p>
	<p>United Kingdom</p>	<p>Intervention: EarlyBird</p>		<p>Differences between EarlyBird and Licensed User sites: Parental stress were higher at T2 but declined between T3 and T4 for the EarlyBird sites. License User sites started at lower levels and had a weaker decline. For socialisation there were significant improvements between T3 and T4 than between T2 and T3, the opposite was found for License User sites.</p>	

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					Parents felt more confident about managing their child and would recommend it to other parents.					
Anderson (2006)	<p>Study 1: To evaluate the EarlyBird intervention</p> <p>Study 2: To establish whether there was a change over-time after participation in the EarlyBird intervention</p>	<p>Study 1: 54 families who have children diagnosed with ASD</p> <p>Study 2: 8 families who have children diagnosed with ASD</p> <p>New Zealand</p>	<p>Study 1: Non-randomised Control Study: Prospective Cohort Study</p> <p>Study 2: Non-randomised Control Study: Prospective Cohort Study</p> <p>Intervention: EarlyBird</p>	<p>Study 1: Parents perceptions of the severity of symptoms and parental stress: Child Autism Rating Scale – Parent Version</p> <p>Study 2: Evaluation of skills: Autism – Parenting Questionnaire</p> <p>Study 2: Evaluation of skills: Autism – Parenting Questionnaire</p> <p>Assessing family relationships, personal growth, and familial functioning: Family Environment Scale</p> <p>Parental stress: Parental Stress Index</p> <p>Parent behaviour observation and verbal behaviour: Using video recordings</p>	<p>Study 1: Parents showed a significant increase in the skills that they learnt, but there were no significant differences in parents perceptions of the severity of the symptoms and parental stress post-intervention.</p> <p>Study 2: Parents showed a significant increase in their ASD specific skills and knowledge over time. Families employed more control within the familial environment post-intervention.</p>	Study 1: The study developed an instrument to assess parents knowledge and skills for ASD interventions which adds to current assessment of interventions. The study also made use of both a normal and condensed version of the intervention. Even though there were no significant differences in the findings between these 2 intervention options it still deviates from the EarlyBird intervention as set out. The condensed	Y	Y	Y	AC, D, IM, P, AD, IN, EX, ET

						version was not described in detail.				
						Study 2: Small sample so results should be interpreted with caution.				
Murray (2011)	To examine the impact of the EarlyBird and EarlyBird Plus interventions on the parent-child relationship and family well-being	EarlyBird/ EarlyBird Plus: 23 parents who have children diagnosed with ASD  Comparison group: 18 parents who have children diagnosed with ASD  United Kingdom	Non-randomised Controlled Design: Controlled before -and- after study  Intervention: EarlyBird EarlyBird Plus	Expressed emotion: Autism-specific Five Minute Speech Sample (AFMSS)  Level of participation in family activities: Family Well-being Checklist	No significant differences in terms of expressed emotion and family activities were found for parents who attended the intervention and those who did not attend.	One of the first studies to make use of both EarlyBird and EarlyBird Plus programmes in one study. However, the study did not provide separate results for EarlyBird versus EarlyBird Plus intervention – which could have allowed for the examination of possible differences in impact between the two interventions.	Y	Y	N	ET
Stevens (2013)	To evaluate the efficacy of EarlyBird and EarlyBird Plus intervention	136 participants: EarlyBird: 48 parents / carers  EarlyBird Plus: 58 family members and 30 supporting professionals	Quasi-experimental Design  Intervention: EarlyBird EarlyBird Plus	Perceptions of intervention: Post-intervention questionnaires	Parents and professionals showed significant change in knowledge post-intervention. Participants of	The paper provides a good description of the EarlyBird and EarlyBird Plus programmes and provides insight into differences in knowledge and	X	Y	N	AC, P, AD, EX, ET

United Kingdom				EarlyBird Plus intervention indicated less change than those of EarlyBird intervention	understanding of ASD across the two programmes. The study indicated differences across programmes descriptively, but did not test for any significant differences across groups.
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**QUALITATIVE RESEARCH DESIGNS**

Whitaker (2002)	Descriptive paper about an educational support project that included the EarlyBird intervention	35 000 under five years olds with a diagnosis of ASD and their parents.  United Kingdom	Quasi-experimental Design  Intervention: EarlyBird as part of a support project	Perceptions of intervention: Intervention evaluations	Parents rated the interventions as useful, particularly with regards to autism knowledge, management and techniques, and promoting expressive and repetitive communication.	Integrating the intervention as part of a bigger support project allowed for a greater access to EarlyBird intervention. The study only made use of post-intervention evaluations and could have made use of more objective measures as part of a RCT to examine the efficacy of the intervention.	Y	N	N	AC, IM, P, AD, IN, EX, ET
Birkin (2008)	To determine: (i) the extent to which families find out about the availability of the EarlyBird intervention, (ii)	Study 1: 77 parents/carers who have children with ASD  Study 2:	Study 1: Descriptive study  Intervention: EarlyBird Study 2:	Study 1: Knowledge of EarlyBird intervention, reasons for non-participation, barriers to access, and for ethnic minority	Study 1: 64 participants heard about EarlyBird, 28 of which had participated in the	Study 1: One of the few studies to examine the EarlyBird intervention outside of the UK	Y	N	N	AC, D, P, IN

the factors that influence their decisions to participate, and (iii) what the barriers are that prevent participation	12 key informants from three ethnic minority groups (Maori, Pasifika and Korean)  New Zealand	Descriptive study  Intervention: None	groups: Retrospective study designed survey questionnaire.  Study 2: Cultural barriers to uptake of EarlyBird intervention: Semi-structured interview.	intervention. Significant differences were found in terms of ethnicity between those who attended the intervention and those who did not. Ethnic minority groups were less likely to participate. Participants also listed the programme as not being convenient in terms of time as one of the barriers for non-participation.  Study 2: Participants listed conducting an intervention in English as a barrier. Also time constraints, shyness coming from minority groups were reasons ethnic minority groups	and provided some insight into the feasibility of the intervention among a non-UK sample and considering ethnic minority groups. The study however made use of a small sample therefore results should be interpreted with caution.  Study 2: The study provides some of the barriers that ethnic minority groups have in intervention participation which could be addressed in an attempt to make an intervention more feasible.
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					listed for non-participation.					
Halpin (2011)	Descriptive paper on the EarlyBird intervention as part of an interagency / multidisciplinary team	N/A United Kingdom	Descriptive study  Intervention: EarlyBird	Perception of intervention / efficacy: Post-intervention questionnaires	Parents reported finding the intervention useful in understanding their children, and feeling more confident in their parenting.	The study implemented the intervention as part of a multidisciplinary team which allowed for more trained EarlyBird facilitators to access more parents. The study, however, failed to describe the number of participants as well as the analysis and presentation of the results.	Y	Y	N	AC, D, IM, P, AD, IN, EX, ET
Clubb (2012)	To evaluate the efficacy of EarlyBird and EarlyBird Plus interventions	EarlyBird: 38 families EarlyBird Plus: 47 families and 45 school staff  United Kingdom	Descriptive study: Qualitative - case study design  Intervention: EarlyBird EarlyBird Plus	Perception of intervention / efficacy: Post-intervention questionnaires	Themes generated from parents' perceptions included: increased knowledge of ASD, diagnosis acceptance, increased emotional well-being, problem solving skills and school-home partnership.  Trainers perceptions of	The study added to what is currently known by considering what trainers considered as being effective in the interventions. The study could've presented differences in themes for those who attended the EarlyBird versus the EarlyBird Plus programme to establish any similarities or	Y	N	N	AC, P, AD, IN, ET

					the intervention included: shared understanding of ASD, benefits in multi-professional teams, and home visits provided parents with a safe space.	differences between the two programmes.				
Montgomery, (2012)	To evaluate EarlyBird intervention in Camden	6 families with a child with ASD. United Kingdom	Descriptive study: Qualitative – Case study design  Intervention: EarlyBird	Perception of intervention: Post-intervention questionnaires	Parents reported increased understanding of ASD, and gained behaviour and communication techniques to apply in the home.	The report presents one of the first thorough descriptive evaluations of EarlyBird. Study relied largely on qualitative data from evaluation forms and has presented lots of findings that have previously been reported in the UK.	Y	Y	N	AC, P, AD, IN
<b>MIXED RESEARCH DESIGNS</b>										
Hardy (1999)	To evaluate the EarlyBird intervention, and identify significant changes in parental stress, perceived adaptive functioning of the child and interaction.	30 families (18 – experimental groups; 12 – control groups) United Kingdom	Non-randomised control study: Repeated measures design  Intervention: EarlyBird	Parent perceptions of how intervention contributed to significant change: Post-intervention feedback forms  Child developmental characteristics: Vineland Adaptive Behaviour Scales-Revised	Significantly lower parental stress among parents attending the EarlyBird intervention – this persisted at 6-month follow-up. Reduced language displayed by	Good attempt at examining the effect of the EarlyBird intervention, not only for parents but also on the perceived functioning of the child. Made use of a non-randomised	Y	Y	Y	AC, P, AD, ET

				Parental Stress: Parental Stress Index	parents during structured play and parents	allocation to control and experimental group.				
				Confirm diagnosis of ASD: Childhood Autism Rating Scale	viewed their children as 'less autistic' after the					
				Child's level of communication with parent: Receptive-Expressive Emergent Language Scale	intervention. Increased adaptive functioning and communication levels were also seen.					
				Parent Confidence: Parent Confidence questionnaire						
Morris (2002)	To evaluate the EarlyBird intervention	6 parents of children diagnosed with an ASD.  United Kingdom	Quasi-experimental Design: Interrupted time series study  Intervention: EarlyBird	Child communication: Communication questionnaire  Parent Knowledge: Post-programme questionnaire  Perceptions of intervention: Intervention evaluations	3 parents rated great changes in child communication, 2 rated somewhat of a change and 1 did not notice marked changes.  Parents rated programmes as helpful and understood more about their child's diagnosis, understood behaviour and increase in previous knowledge	Good attempt at evaluating the EarlyBird intervention. No use of RCTs to assist in establishing cause and effect between treatment and outcome.	Y	Y	Y	AC, P, IM, AD, IN, EX, ET

					post-intervention.					
Engwall (2003)	To evaluate the EarlyBird intervention focusing on: parental stress, knowledge of autism as well as child communication and behaviour	24 families of children diagnosed with ASD.  United Kingdom	Quasi-Experimental Design: Interrupted time series study  Intervention: EarlyBird	Parental stress: Parenting Stress Index – Short Form  Perception of intervention: EarlyBird intervention evaluation	Parental stress significantly reduced post-intervention.  Most parents felt more confident about managing their child, improved knowledge and communication post-intervention.	The study highlighted how the intervention found a significant reduction in parental stress post-intervention. One of the limitations in that a non-randomised controlled study design was used.	Y	Y	N	AC, IM, ET
McCauley (2010)	To establish if one can measure individual patterns of development, and the factors that appear to be important in encouraging any measured development of a group of pre-school children with ASD  Establish views of parents participating in EarlyBird. Perceived improvements in child's development.	3 parents who have children diagnosed with ASD.  United Kingdom	Quasi-experimental Design  Intervention: EarlyBird	Social interaction, communication, stereotyped behaviour, ASD severity: Gilliam Autism Rating Scale (2 <sup>nd</sup> ed)  Adaptive behaviour (communication, social interaction skills, adaptive behaviour): Vineland Adaptive Behaviour Scales (2 <sup>nd</sup> ed).  Conduct problems, inattention/hyperactivity, emotional symptoms, peer problems, and prosocial behaviour: Strengths and Difficulties Questionnaire  Cognitive ability: British Ability Scale (2 <sup>nd</sup> ed)	Parents reported reduced stress.	Parental stress was not measured objectively.	Y	N	Y	AC, D, P, AD, IN, ET

	Impact of and challenges of accessing EarlyBird			Perceptions about programme: Semi-structured interview						
Peters (2014)	To evaluate how learning support assistants benefit from EarlyBird Plus intervention	Questionnaires: Sample size unknown  Semi-structured interviews: 3 parents/ caregivers, 3 learning support assistance, and 3 school staff members who did not attend intervention  United Kingdom	Quasi-Experimental Design: Quantitative – Descriptive statistics Qualitative – Case study design  Intervention: EarlyBird Plus	Perceptions of intervention: Post-intervention questionnaire & semi-structured interviews	Learning support assistants reported an increase in knowledge about autism, and felt confident about using strategies learnt post-intervention.  The themes generated from the interviews included: increase in knowledge and confidence in using strategies learnt, gained new strategies and noted improvements in child's behaviour, consistency in strategy use across home and school	The study provided insight into the learning support assistants perceptions of the benefits of EarlyBird Plus programme. However the study failed to mention sample size of participants who completed questionnaires.	N	N	N	AC, AD, ET
Cutress (2014)	To report parents views of the EarlyBird Plus intervention	120 parents / carers from 25 EarlyBird Plus intervention groups	Quasi-experimental design	Perceptions of intervention: Post-intervention questionnaire	Parents / carers found the intervention beneficial and would	The study provided a good description of parents perceptions of	Y	N	N	AC, D

United Kingdom	Intervention: EarlyBird Plus	recommend it to other parents. They also felt more confident in meeting the needs of their children. Key themes parents alluded to included: knowledge about ASD, learning communication and behaviour	the EarlyBird Plus programme. Study only made use of a post-intervention evaluation and did not make use of any pre-intervention evaluation and also did not use any objective measures to evaluate change.
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**QUALITATIVE STUDIES**

**Percentages**

14/18 – 78%	9/18 – 50%	5/18 – 28%
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**Abbreviations:**

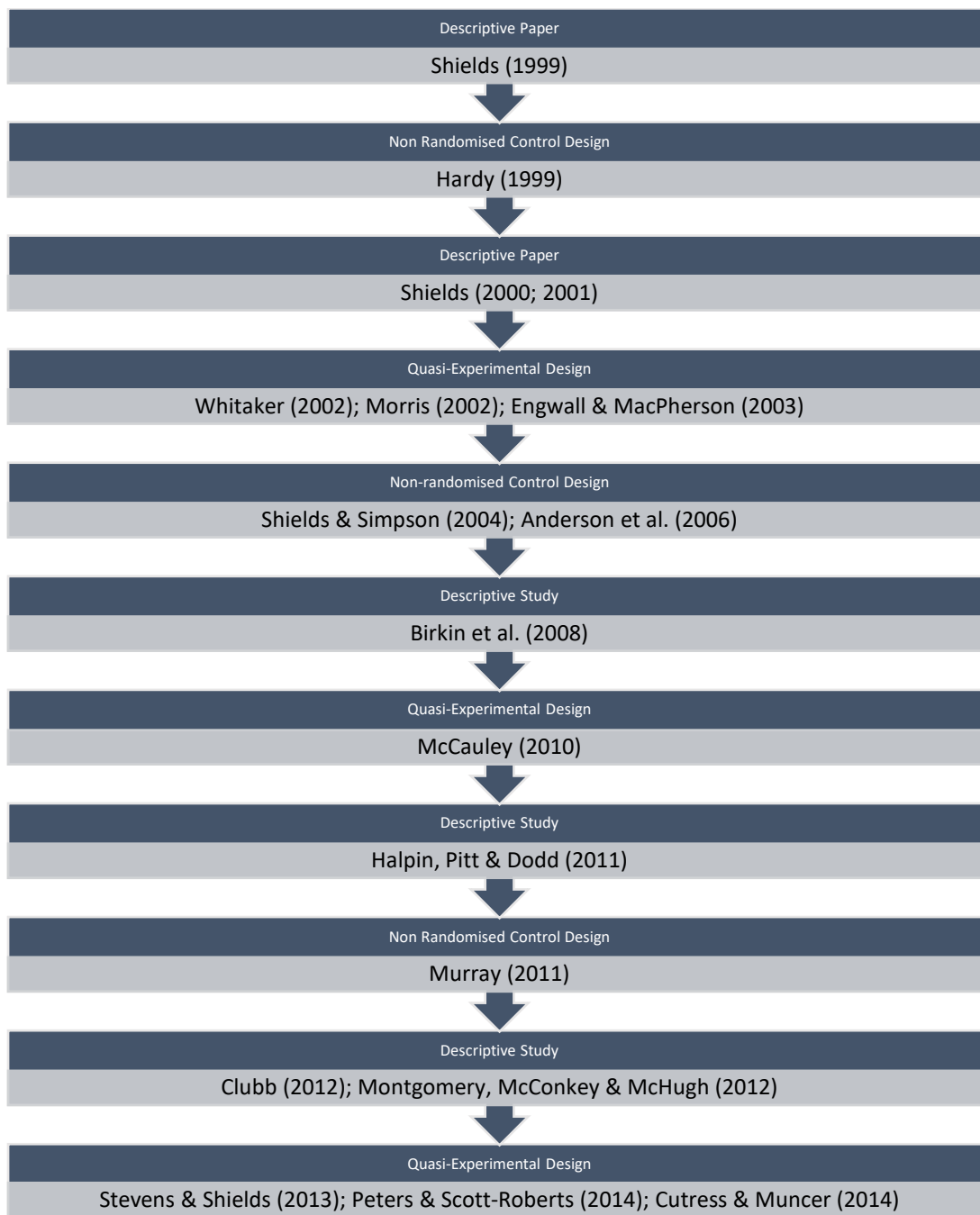
- N – Not part of the study
  - Y – Part of the study, commented on in some manner (not necessarily part of the study)
  - Ac – Acceptability
  - D – Demand
  - Im – Implementation
  - P – Practicality
  - Ad – Adaption
  - In – Integration
  - Ex – Expansion
  - ET – Limited efficacy testing
  - RCT – randomised controlled trial
-

### 2.3.2 Study design

The results presented in Table 2.2 show that seven studies were descriptive in design with a focus either on describing the *EarlyBird* and *EarlyBird Plus* parenting programmes, or describing the parental perceptions of the programmes. Among the descriptive studies, four employed a qualitative method component to examine participants' perceptions of the *EarlyBird* parenting programme. There was no explicit mention of the data analysis technique employed in three of the four studies, with the exception of one mixed-method study (Birken et al., 2008) which made use of content analysis.

The results presented in Table 2.2 suggest that of the 18 articles included in the review, four (22%) made use of a quantitative research design (non-randomised control design = 3; quasi-experimental = 1), and three (17%) were factual descriptions of the *EarlyBird* and *EarlyBird Plus* programmes without any data. Five studies (28%) were qualitative in nature (semi-structured interviews = 2; perceptions using post-evaluation forms = 2; reflections and descriptions = 1), an additional six studies (33%) made use of mixed-method research designs (combination of post-evaluation and outcomes measured data used = 6). There was no explicit mention of the data analysis technique employed in the qualitative studies, with the exception of one mixed-method study (Birken et al., 2008) which used content analysis.

Eleven studies aimed to evaluate the efficacy of the *EarlyBird* and *EarlyBird Plus* parenting programmes. The chronological evaluation of study designs (see Figure 2.2) used in *EarlyBird* and *EarlyBird Plus* programmes suggested that studies started off being largely observational in nature (more descriptive) but then shifted towards more experimental studies, typically non-randomised controlled trials. Hardy (1999) performed the first study using an experimental design when evaluating *EarlyBird* research. To date, no randomised controlled trials have been published and no studies evaluating programmes implemented in low-resource settings, such as Low- or Middle-Income Countries, or in any non-English speaking countries.



**Figure 2.2. EarlyBird Study Design Flowchart**

Six of the descriptive studies in the review made use of parental perceptions of the programmes as an outcome measure using the EarlyBird and EarlyBird Plus programme feedback questionnaires, as shown in Figure 2.2 (Whitaker, 2002; Halpin, Pitt & Dodd, 2011; Clubb, 2012; Montgomery, McConkey & McHugh, 2012; Peters & Scott-Roberts, 2014; Cutress & Muncer, 2014), while four made use of non-randomised controlled designs and included parental stress using the parental stress index (Hardy, 1999; Engwall & MacPherson, 2003; Shields & Simpson, 2004; Anderson et al., 2006), and/or adaptive behaviour using the Vineland Adaptive Behaviour Scale (Hardy, 1999; Shields & Simpson, 2004; McCauley, 2010). One study used the family well-being checklist, designed to assess how families receiving early intervention change in their ability to participate in family activities (Murray, 2011).

### *2.3.3 Parent & child changes*

Fourteen of the 18 studies (78%, see Table 2) reported on parental perceptions about the programmes. Nine of the 18 articles (50% reported on parental changes using pre-post questionnaire data). Most studies reported an increase in parental knowledge about ASD (n=8; 44%) as being one of the most common changes, followed by increased confidence in parenting their child with ASD (n=5; 28%), and a decrease in parental stress (n=4; 22%).

Five of the 18 articles (28%) reported changes in children using pre-post questionnaire data (Hardy, 1999; Morris, 2002; Whitaker, 2002; Shields & Simpson, 2004; Peters & Scott-Roberts, 2014). The changes highlighted included improved communication and behaviour in children after their parents participated in the EB/EBP programmes (n=5, 28%). The reported changes were observed across the different study designs, and quantitative or qualitative methodologies used.

### *2.3.4 Strengths and weaknesses of the studies*

The data extraction in the review highlighted a number of strengths and weaknesses in the studies on the EarlyBird and EarlyBird Plus parenting programmes. One of the main strengths of the studies were the comprehensive descriptions of the EarlyBird and EarlyBird Plus parenting programmes as seen in three of the studies (Shields, 1999; Shields, 2000; Stevens & Shields, 2013), where the studies described the EarlyBird programmes, their key components, session structure and outcome measures used. Hardy's study (1999) was one of

the few that examined the efficacy of the interventions as well as changes in the perceived functioning of the child, including such measures as the Child Autism Rating Scale, the Receptive-Expressive Emergent Language scale, and the Vineland Adaptive Behaviour Scale (Bzoch, League & Brown, 2003; Ozonoff, Goodlin-Jones & Solomons, 2005; Sparrow, Balla & Cicchetti, 1984). The parenting programmes were implemented and evaluated among ethnic minority groups (Maori, Pasifika and Korean) in one New Zealand study, but this was the only investigation of EB/EBP in potentially lower-resourced families. Research by Birkin et al. (2008) highlighted the use of the intervention among groups outside of the United Kingdom and barriers to access for such groups. Clubb's (2012) study shed light on what EarlyBird trainers considered to be effective in the interventions using a qualitative methodology. A clearer understanding of ASD and the benefits of working in multi-professional teams were considered as being effective in the interventions.

A number of limitations were highlighted. These included the use of only post-intervention evaluations in two of the studies (Whitaker, 2002; Cutress & Muncer, 2014). In addition, there was a large reliance on the use of qualitative data from the EarlyBird evaluation form to determine the efficacy or perceptions of the intervention in eight of the studies (Hardy, 1999; Whitaker, 2002; Morris, 2002; Engwall & MacPherson, 2003; Montgomery, McConkey & McHugh, 2012; Stevens & Shields, 2013; Peters & Scott-Roberts, 2014; Cutress & Muncer, 2014). One of the studies in the review made use of a condensed version of the EarlyBird programme and, when compared with the normal EarlyBird intervention, no differences were found in the findings between the two intervention groups (Anderson et al., 2006). Unfortunately, the condensed version of the programme was not described in detail, making it difficult to draw conclusions. One of the studies which made use of both the EarlyBird and EarlyBird Plus parenting programmes did not present the results regarding efficacy between the two interventions separately which might have indicated differences for the EarlyBird and EarlyBird Plus programmes (Murray, 2011). Overall, the study samples were small (ranging from 3 to 136 participants) and the studies were largely non-randomised controlled in design. Evidence-based medicine guidance indicates that the overall level of evidence could be rated, according to the widely used in evidence-based practice National Comprehensive Cancer Network (NCCN) guidelines, as level 2B. This is reported to be a lower level of evidence (e.g.

no randomised controlled trials) but with uniform consensus and no major disagreement (Poonacha & Go, 2011).

### *2.3.5 Feasibility*

Apart from efficacy, we were particularly interested in feasibility of the EB/EBP programmes. Table 2 indicates all articles that commented on any aspects of feasibility as described by Bowen (2009). Acceptability was formally examined in 11/18 (61%) of the articles, and broadly referenced in an additional 6 articles. All of the research that measured this area indicated that parents found the programmes acceptable. Limited efficacy testing was performed using outcome measures in 13/18 articles (72%) (The results of those are reflected under 2.3.3). No formal or measured evaluation of other aspects of feasibility were identified. Some comments were made about practicality by 11/18 (61%); on integration by 11/18 (61%); programme adaption by 10/18 (56%); implementation by 7/18 (39%); expansion by 7/18 (39%) and demand by 5/18 (28%). These comments on the different areas of feasibility covered a broad range of topics making a concise summary of them difficult. In general, they reflected on some of the challenges and solutions relating to practicality, integration and implementation as well as demand for the programme. They also reported on suggestions for programme adaptation and expansion by both parents and professionals.

## **2.4 Discussion**

Given the importance of Parent Education and Training (PET), and the widescale implementation of the EarlyBird and EarlyBird Plus (EB/EBP) programmes, the current study set out to perform a comprehensive scoping review of all peer-reviewed literature on these programmes in order to establish the current evidence-base for these PET programmes, and to identify key research and implementation gaps.

The study identified only 18 peer-reviewed and grey literature publications on the programmes. All came from two English-speaking countries, namely the UK and New Zealand. The majority of studies were descriptive or non-randomised controlled trials and no randomised controlled trials (RCT) of EB/EBP were identified. The majority of studies

evaluated acceptability to parents and/or performed limited efficacy testing. Far fewer studies evaluated other aspects of feasibility, such as demand, expansion and implementation. A handful of studies used standardised measures outside the EB/EBP specific outcome measures and most focused on parental outcome. Taken together, the current level of evidence for EB/EBP based on this review provides lower-level, but consensus support for the efficacy of the programmes. This would equate to a 2B level of evidence to grade the strength of the evidence (NCCN Clinical Guidelines).

On the one hand, the findings presented here clearly suggest the need for randomised controlled trials of EB/EBP to improve the level of evidence for the efficacy of this PET. However, there is currently no consensus evaluation framework for such programmes in ASD. For example, to date a certain range of outcome measures have been used and there is no agreement on whether outcomes of PET should only be measured in parents or also in their children. Apart from selection of outcome measures, some authors such as Hardy (1999), suggested the need for longer-term follow-up of training and commented on the potential to use video recordings (routinely collected in EB/EBP) as an objective data source to quantify parent-child interactions.

In addition to the challenges of finding suitable outcome measures and timeframes for outcomes, randomised controlled trials are methodologically complex, time-consuming and resource-intensive. Importantly, Shaw, Larkin and Flowers (2014) commented that so-called evidence-based practices must be applicable and adaptable to real-world settings and be able to take into account cultural and psychosocial context. To do this, research must broaden its evidence-base beyond evaluation of efficacy to include issues of context, acceptability, cultural appropriateness and accessibility in the development and implementation of interventions (Shaw, Larkin and Flowers, 2014). Such a broad implementation science approach will clearly require mixed method approaches and a broad multi-source evaluation framework.

Progress on how best to assess feasibility, particularly in mental health services in High-Income-Countries (HIC) has improved (Brooke-Sumner, Lund & Petersen, 2016), for example the SAFE (Structured Assessment of FEasibility) guidelines is a measure designed to assess the

feasibility of implementing a complex intervention within mental health services in the National Health Service (Bird, 2014). Such standardised guidelines are developed for well-resourced and HIC settings and are rarely employed in LMIC or low-resource settings. Given the clear need and in keeping with the principles of distributive justice, future research may focus on complex interventions like EarlyBird in LMIC and could benefit from the use of already established guidelines like SAFE and the Medical Research Council's guidance for developing and evaluating complex interventions (Craig et al., 2008).

One limitation of the study which might have arisen, is the subjectivity of the data abstraction process. Efforts were made to reach consensus between the two independent reviewers and consultation with the senior author reduced the potential for reporting bias.

## **2.5 Conclusion**

The EarlyBird and EarlyBird Plus programmes are widely used as a first-line psychoeducation programme for parents of children who have been diagnosed with ASD. In spite the broad implementation, this review identified only lower-level strength of evidence for the efficacy of the programmes, and most evidence came from HIC. We recommend that randomised controlled trials should be considered to establish a higher level of evidence, and advise further research on EB/EBP, particularly in Low- and Middle-Income Countries. Apart from limited efficacy testing, relatively little implementation science research has been done on EB/EBP to determine the feasibility of such programmes in the real world. Examination of broader construct of feasibility, covering integration; implementation; demand; accessibility; adaptation and expansion, alongside efficacy testing, could be invaluable.

## **2.6 Chapter summary**

EarlyBird (EB) and EarlyBird Plus (EBP) are Parent Education & Training (PET) programmes designed by the United Kingdom (UK) National Autistic Society (NAS) in 1997 and 2003, having been delivered to more than 27,000 families in 14 countries. These group-based programmes aim to 1) support parents immediately after diagnosis of Autism Spectrum Disorder (ASD), 2)

empower parents, encouraging a positive perception of their child's ASD, and 3) help parents establish good practice. In the absence of any previous comprehensive review, we performed a scoping review of all peer-reviewed publications on EB/EBP. A search was conducted between February and June 2016 using EBSCOhost, Sabinet, SAGE Journals, Directory of Open Access Journals, BioMed Central, Scopus, Science Direct and grey literature. Two reviewers independently screened titles and abstracts for inclusion. Eighteen articles were identified – 16 from the UK and two from New Zealand. We reviewed the context, study populations, design, outcome measures, whether focus was on parental perception, parental change or child changes, and programme feasibility. Strong parental support for the acceptability but lower-level evidence of efficacy of EB/EBP was found. Future research should consider randomised controlled trials. There is no research on EB/EBP in low-resource settings, therefore we recommend broader feasibility evaluation of EB/EBP including accessibility, cultural appropriateness and scalability.

# Chapter 3

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## Parent Education & Training for Autism Spectrum Disorders around the globe – scoping the evidence

### 3.1 Introduction

The World Health Organization (WHO) resolution on Autism Spectrum Disorder (ASD) has emphasised the importance of psychoeducation to parents and carers of children with ASD (WHO, 2014). In addition, the UK-based Autism Education Trust emphasised that “high on the agenda of parents/carers and professionals alike is providing knowledge and information on the autism spectrum...to parents/carer and other family members” (Jones et al., 2008, p102).

Providing ‘knowledge and information’ to parents/carers is referred to using many different terms, including ‘parent training’, ‘parent education’ and ‘psychoeducation’. In an attempt to standardise terminology, Bearrs and colleagues (2015) suggested a taxonomy and proposed differentiating between ‘parent support’ programmes where the parent is the direct beneficiary of the intervention, and ‘parent-mediated interventions’ where parents are coached to work directly with their children, making the child the direct beneficiary. In a recent review of EarlyBird (EB) and EarlyBirdPlus (EBP), two UK-developed parent education programmes, we acknowledged that EB/EBP and many other parent education or support programmes are in actual fact hybrid models including some ‘parent support’ (e.g. lectures and discussions with parents) and some ‘parent-mediated’ components (e.g. home visits or video guidance to observe and advise on parent-child interactions). For that reason, we have opted to use the term ‘Parent Education & Training’ (PET) to refer to EB/EBP and similar programmes (Dawson-Squibb, Davids & de Vries, in press; chapter 2). We defined PET as programmes that pass on information and/or skills to parents/carers using a range of modalities (didactic; role-play; discussions; video guidance, etc.) in a setting where parents/carers and trained facilitators are the direct participants. This implies that the

emphasis is on knowledge transfer to parents/carers and that the priority participants are parents and facilitators and not the parent-child dyad (Dawson-Squibb, Davids & de Vries, in press).

In our scoping review of all peer-reviewed and grey literature on EarlyBird (EB) and EarlyBird Plus (EBP) we identified only 18 publications, all from the UK or New Zealand, despite the fact that the programme has been delivered in 14 countries to over 27,000 families to date. Results showed a high level of acceptability to parents, but relatively low-level evidence of efficacy, across a range of outcome measures and study designs. We identified no published randomised controlled trials (RCT) of either EB or EBP and limited consideration was given to other factors of potential importance to implementation, such as accessibility; demand; expansion and cultural appropriateness. Interestingly, we were not able to identify any consensus evaluation framework for PET programmes in ASD (Dawson-Squibb, Davids & de Vries, in press).

In part, the EB/EBP review identified a number of clear next steps in relation to these specific PET programmes. However, it also raised a question about the current evidence- base and implementation science knowledge base about PET more broadly. For instance, in a recent narrative review, Preece & Trajkovski (2017) identified only 12 publications that met their criteria for ASD ‘parent education’ programmes. The authors reported positive evidence for the programmes (e.g. reducing parental stress, improved coping, confidence and understanding of ASD), but commented on the need for further research in the field (e.g. longitudinal studies) and recommended that additional cultural considerations be investigated in research. Taken together, both reviews (Preece & Trajkovski, 2017; Dawson-Squibb, Davids, de Vries, in press) underlined the need for a broader review and exploration of the evidence-base for PET programmes.

We therefore set out to perform a broad scoping review of PET with three aims:

- 1) to describe the characteristics of PET programmes (e.g. location; structure; length; modalities of delivery; intervention objectives);
- 2) to examine the research methodologies and evidence-base of the programmes (e.g. study design; measures; outcomes; quality of research) and

3) to investigate which implementation-related factors had been explored to date (e.g. cultural appropriateness; manualisation of interventions; fidelity measurement; cost).

### 3.2 Methods

A scoping review methodology was employed using the recommended guidelines as outlined by Arksey and O’Malley (2005) to address the aim of the review.

#### 3.2.1 Terms and definitions

The aim of the review was to establish research relating to PET programmes that existed for parents/carers of children with an ASD. Given that the majority of ASD research to date has been performed in the USA (Franz et al., 2017), we specifically chose to focus on publications from outside the USA. Terms and definitions to guide the review were selected *a priori*, as outlined in Table 3.1 below.

**Table 3.1. Terms and definitions**

Term	Definition
Parent Education & Training (PET)	The passing on of information or skills to parents using a range of modalities (didactic; role-play; discussions; video guidance) in a context where parents/carers and trained facilitators are the direct participants. The primary emphasis is on knowledge transfer to parents and the priority participants are parents/carers and not the parent-child dyad.
Autism Spectrum Disorder	As defined in the DSM-5 and including the DSM IV/ICD-10 Pervasive Developmental Disorders (e.g. Asperger’s Disorder, Pervasive Developmental Disorder Not Otherwise Specified).

### 3.2.2 Search strategy

During the months of March and May 2017, a search was conducted using the following electronic databases: EBSCOhost (Academic Search Premier, Africa-Wide, Medline, CINAHL, ERIC, Health Source: Nursing Academic Edition, PsycArticles, PsycINFO and SocIndex), SAGE Journals, Science Direct and Springer Link with no date restrictions. The searches were independently conducted by two reviewers (the author and a postdoctoral researcher) using Boolean logic and operators for the following keywords: *Autism, ASD, Autism Spectrum Disorder, Asperger's, Parent Education Programmes, Parent Education Groups, Parent Psychoeducation, Parent Education Training, and Parent Education*. The studies yielded through searching the databases had their titles and abstracts screened using the inclusion criteria in the review (discussed below 3.2.3). The screening process was conducted by two reviewers (the author and a postdoctoral researcher), followed by the retrieval of full texts of studies that met the inclusion criteria. During the screening and retrieval process, a third reviewer was consulted in the event of an impasse to assist in determining whether the study adequately met the inclusion criteria.

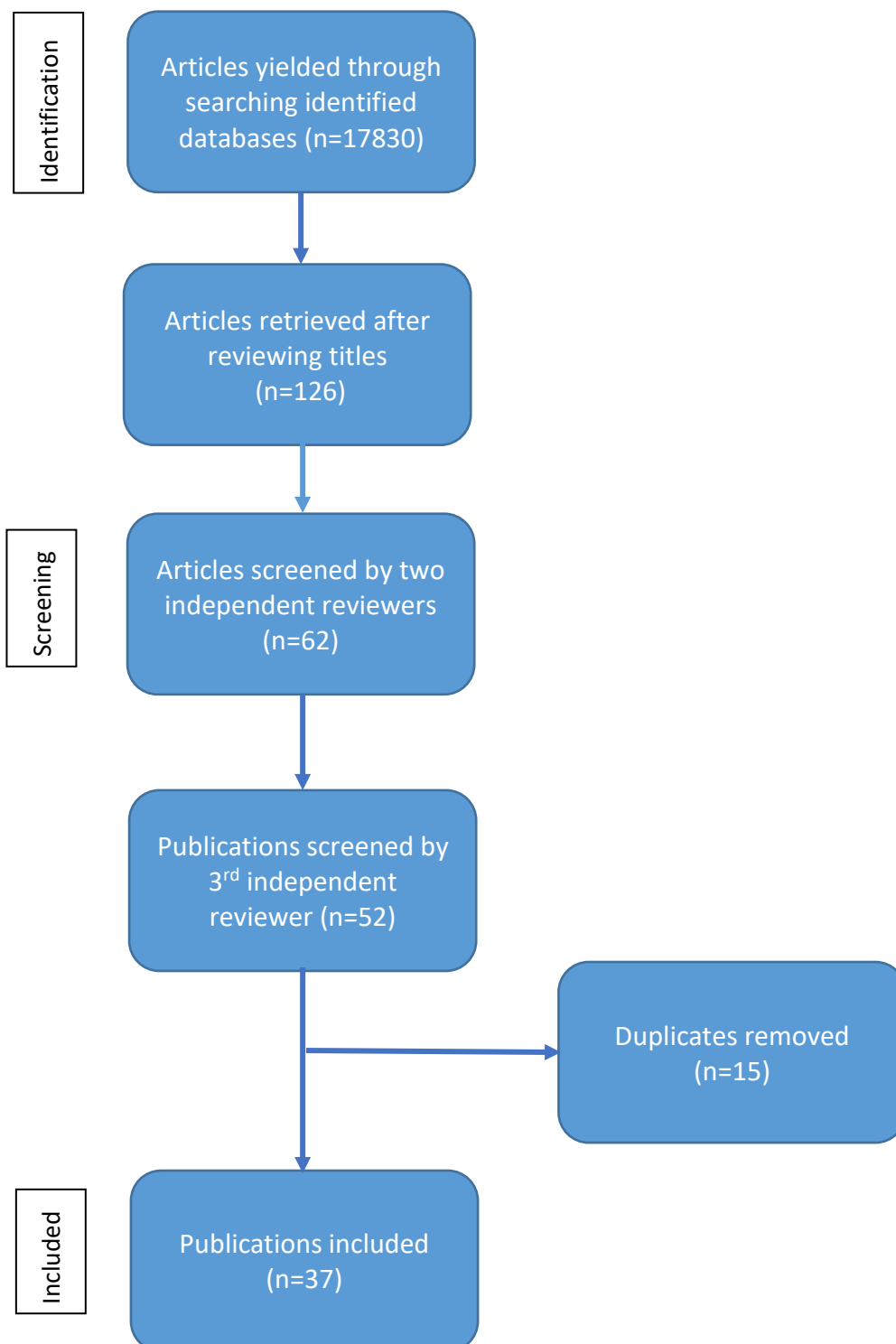
### 3.2.3 Inclusion criteria

A study needed to meet the following *a priori* inclusion criteria to be considered for inclusion in the review: 1) had to be published in a peer-reviewed, accredited journal; 2) had to make use of a parent psychoeducation intervention/strategy aimed at increasing parental knowledge about ASD; 3) the child with ASD was not present in the therapy/consultation room when the psychoeducation intervention was being delivered; 4) the study had to make use of parent psychoeducation, as defined in Table 1 and 5) had to have been conducted outside of the USA given the focus on non-USA research and the relatively recent review of ASD parent psychoeducation within the USA (Schultz, Schmidt & Stitche, 2011).

### 3.2.4 Methods of review

Two reviewers (the author and a postdoctoral researcher) conducted the initial search and review of the study titles and abstracts, using Boolean logic and operators. The searches for the databases and keywords as listed above yielded 17,830 studies. The titles and abstracts were screened for eligibility resulting in the exclusion of 17,704 studies due to ineligibility and

duplication across the databases. Duplication resulted when a study appeared more than once across the various database searches. The remaining 126 studies considered for inclusion in the study were independently reviewed by two of the reviewers (the author and postdoctoral researcher) to establish whether the study met the inclusion criteria. This resulted in 62 studies to be considered, of which 52 met the initial screening using the inclusion criteria and 10 studies where there was an impasse. After consultation with a senior third reviewer and screening by all three reviewers, the total number of studies considered for inclusion was 52. The full texts of these 52 studies were then accessed. While accessing the full texts of the studies considered for inclusion, 15 studies were excluded due to duplication, not adequately meeting all the inclusion criteria or were a commentary/editorial without sufficient information about the PET/strategy. One study was excluded on the basis of language (French, where no English translation was available). The final sample therefore included 37 studies. The PRISMA flow diagram for the scoping review is shown in Figure 3.1.



**Figure 3.1. PRISMA Flow Diagram**

### *3.2.5 Data extraction and synthesis*

After screening by the three reviewers, the studies were examined using a narrative synthesis approach. Narrative synthesis was selected to present results given the highly heterogeneous nature of the study designs identified (Guise, Anderson & Wiig, 2014). We considered the use of meta-ethnographic or meta-analytic analyses which did not prove to be viable alternatives in attempting to understand the findings within the review (Guise, Anderson & Wiig, 2014; Davids, Roman & Leach, 2017).

The narrative synthesis approach employed was adapted from Popay and colleagues (2006), and had previously been implemented by Leamy et al. (2011) as well as Davids, Roman & Leach (2017), following a three-stage synthesis approach: (i) developing a preliminary synthesis of findings of included studies, (ii) exploring relationships in the data and (iii) an assessment of the robustness of the synthesis.

The preliminary synthesis of findings of the studies included in the review made use of initial data extraction from two included studies among the three reviewers. The data were extracted following the process of narrative synthesis using a data extraction sheet developed specifically to address the aims and objectives of the current review. After the initial data extraction, the three reviewers came to an agreement about the data extraction fields to be included in the final data extraction table and the associated codes for each of the data to be extracted narratively as part of the first phase of preliminary synthesis of the findings. The second phase involved the exploration of the associations between the studies and the extracted data. The associations were examined and explored through the tabulation of the extracted data in the review. The third phase of examining the robustness of the synthesis was employed by four reviewers (the author, a predoctoral researcher, a postdoctoral researcher and a senior researcher), who independently extracted 12 studies and cross-checked their extraction for inter-extractor reliability. The examination of robustness led to an 84.5% agreement of extracted data among the four reviewers, while an additional 13.5% agreement was reached among the reviewers after an examination of the reasons for differences in the extraction, leading to agreement among all four reviewers. This led to a 2% disagreement in the extraction of data as part of the inter-extractor reliability among the four reviewers. Inter-extractor reliability was achieved by examining the percentage in which all

reviewers extracted similar data across the various fields in the data extraction tables (as outlined in **Table 3.2**).

### *3.2.6 Quality appraisal*

Although no publications were excluded because of quality, an appraisal was completed to provide a general indicator of the quality of publications. A Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) was used for this purpose. The MMAT is generally used as part of the appraisal stage of complex systematic literature reviews. In this case it was used to provide a rough indication of publication methodological quality. An examination of robustness between reviewers in the appraisal stage was 87.2% and an additional 12.8% agreement was reached after an examination of reasons for differences in appraisal. This led to a 0% disagreement between the four reviewers for the quality appraisal stage.

## **3.3 Results**

The results will be detailed below under the headings of the 3 aims: 1) descriptive characteristics of the PET programmes, 2) research methodologies and evidence-base of the identified PET programmes, and 3) implementation related factors.

### *3.3.1 Descriptive characteristics of the PET programmes*

Full details of the descriptive characteristics of all identified publications are presented in Table 3.2.

**Table 3.2. Descriptive characteristics of the PET programmes**

<b>First author (year)</b>	<b>Country</b>	<b>Location of study (rural /urban/both)</b>	<b>Modalities (see key for description of abbreviations)</b>	<b>Trainers' background</b>	<b>Objectives of intervention (see key for description of abbreviations)</b>	<b>Group/ Individual/ Both</b>	<b>How many in group</b>	<b>Length (in hours)</b>
<b>Shields (2001)</b>	UK	Both	Av, G, E, P, I, Hv, D	Professionals who must have prior experience of working with people with ASD	PCSS, IC, UD, UCS, RS, BS, DI	Both	6	24
<b>Sofronoff (2002)</b>	Australia	Urban	D	Not stated	SE, BS, PCSS	Both	N/S	1 group day vs 6 individual weekly sessions (time not given)
<b>Mukaddes (2004)</b>	Turkey	Not stated	D, M	Experienced child educators	UCS, BS, PCSS	Both	NM	10.5
<b>Tonge (2006)</b>	Australia	Both	E, M, Av, I, H	Special educators or psychologists	UCS, BS, PCSS, CS, RD, RS	Both	No mention of group based number	25
<b>Yucel (2007)</b>	Turkey	Not stated	Av, E	Not specified	IKI	Group	Not group based	Not stated
<b>Wang (2008)</b>	China	Urban	D, E, Av, M, G, Hv	Not discussed	UCS, BS, PCSS	Both	15	20

<b>Whittingham (2008)</b>	Australia	Urban	E, I, D	Probationary psychologist enrolled in a psychology programme	UCS, BS, GS, PCSS	Both	4-5	Not stated
<b>Birkin (2008)</b>	New Zealand	Both	Av, G, E, P, I, Hv, D	Interviews done by the authors	PCSS, IC, UD, UCS, RS, BS, DI	Group	NA	Not stated
<b>Keen (2010)</b>	Australia	Urban	Av, Hv, G	Doctoral training students	UCS, BS, PCSS, GS	Both	5	2 day workshop (time not given in hours) and 10x1hour home visits
<b>Mulligan (2010)</b>	Canada	Urban	E, G	Not stated	IKI, UCS	Both	4-5	Not stated
<b>Roberts (2010)</b>	UK	Not stated	Not stated	Two trained co-facilitators supported by a student social worker	BS, RD	Group	8	24
<b>Halpin (2011)</b>	UK	Not stated	Not stated	Not stated	PCSS, IC, UD, UCS, RS, BS, DI	Not stated	Not stated	Not stated
<b>Murphy (2011)</b>	Australia	Urban	E, G, P	Experienced clinicians and researchers in the field of ASD	IKI	Group	Not stated	1 ½
<b>Okuno (2011)</b>	Japan	Urban	G, M, Av, H	Nurse and psychologists trained in parent training	UCS, BS, SH	Group	3-4	9
<b>Papavasiliou (2011)</b>	Greece	Urban	Not stated	Not stated	N/S	Not stated	N/A	Not stated
<b>Pillay (2011)</b>	UK	Urban	I, G, H, P	Consultant child and adolescent	UCS, UD, BS, IC, DI, FS	Group	Not stated	22

				Psychiatrist; consultant clinical psychologist. Both with experience working with ASCCs and their families.				
<b>Samadi (2012)</b>	Iran	Urban	E	Not stated	UCS, PCSS, BS	Both	Not stated	Not stated
<b>Al-Khalaf (2013)</b>	Jordan	Urban	P, D, G	Psychologist with previous experience as a counsellor	UCS, BS, RS, CS, PCSS, IC, DI	Group	5	16
<b>Connolly (2013)</b>	Ireland	Not stated	Not stated	Speech and language therapist and social worker	UCS, PCSS, BS, ER	Group	NA	10
<b>Farmer (2013)</b>	Australia	Rural	P, Av, E, I	Occupational Therapist and head of a centre	UD, UCS, IC, BS, DI, IKI, CS, RS	Group	5-16	12
<b>Samadi (2013)</b>	Iran	Urban	Av, E, G, I	Doctoral studies and previous work experience as a psychologist in Iran	IKI, IC, DI, RD, FS	Group	18-19	7-10.5
<b>Cutress (2014)</b>	UK	Not stated	Av, G, E, P, I, Hv, D	To become a facilitator, professionals must have experience of	PCSS, IC, UD, UCS, RS, BS, DI	Both	6	10 week programme (time not given in hours)

				working with people with ASD				
<b>Ji (2014)</b>	China	Urban	P, Av, G, I	Multi-disciplinary team, including special education teacher (also the mother of a child with ASD), community nurse, psychologist, psychiatrist	BS, CS, DI, RS, UD	Group	Not stated	12
<b>Stuttard (2014)</b>	UK	Not specified	D, G, M, H	Clinical Psychologist	UCS, PCSS, BS, GS, CS	Individual	NA	20
<b>Tellegen (2014)</b>	Australia	Not stated	Not stated	Degree in Psychology and accredited in PCSSTP	BS	Individual	NA	3.88
<b>Tonge (2014)</b>	Australia	Both	G, E, I, H	Special educators or psychologists who had experience working with children with ASD and their parents	CS, RD, UCS, BS, UD, GS, PCSS	Both	4-5	15
<b>Grahame (2015)</b>	UK	Not stated	I, G, Pv, E	Designed to be run by group leaders with experience	BS, UCS	Both	Not stated	16

				working with young children with ASD				
<b>Patra (2015)</b>	India	Not stated	G, I	Psychiatrist	UCS, RS	Group	Not stated	24
<b>Yu (2015)</b>	China (Hong Kong)	Urban	G	Not stated	UCS, BS	Group	8	3months (Not given in hours)
<b>Gaad (2016)</b>	United Arab Emirates	Not stated	D, Av	Professor in special education	UCS, PCSS, BS, CS	Group	Not stated	30
<b>Harrison (2016)</b>	Tanzania	Urban	D, E, M	Swahili interpreters and those with PhD in Clinical Psychology and extensive experience working with children with ASD and their families	UCS, BS, PCSS	Group	NA	Variable
<b>Kazuteru (2016)</b>	Japan	Not stated	G, Av, I, D, R	Not stated	RS, CS, UCS, FS	Group	4-8	12
<b>Stuttard (2016)</b>	UK	Urban	D, P, Av, G	Social workers, Psychologists, teachers, ASD specialist teachers and teaching assistants	UCS, PCS, BS, IC	Group	6	18
<b>Tolmie (2016)</b>	Australia	Both	Hv, E	Speech pathologist, Occupational	IC, SS, UCS, BS, PCSS, IKI, FS	Group	N/A	Variable

				Therapist, or Psychologist				
<b>Blake (2017)</b>	Bangladesh	Rural	D, Av, G	Child Psychologist	UD, UCS, BS	Both	5	6 hours
<b>Ilg (2017)</b>	France	Not stated	P, H, E, Hv	Psychologist and Child Psychiatrist. Home visits conducted by doctoral student	UCS, , BS, PCSS, GS, IKI	Group	4-6	24
<b>Preece (2017)</b>	Croatia, Cyprus, former Yugoslavian Republic of Macedonia	Urban	None – programme bring developed	None – programme being developed	CS, UCS, BS	Programme being developed	Programme being developed	None – programme being developed
<b>Summary</b>	Australia – 9 UK – 8 China – 3 (one of those from Hong Kong) Iran – 2 Japan – 2 Turkey – 2 Ireland – 1 Bangladesh – 1 India – 1 Ireland – 1	Rural – 2 Urban – 17 Both – 5 Not stated – 13	G – 20; E – 17; Av – 14; D – 14; I – 13; P – 9; Hv – 7; M – 5; H – 5; Pv – 1; R – 1; Not Stated – 5.	Psychologists – 13; Professionals with experience with ASD/experience d clinicians – 5; psychiatrists – 4; specialist educators – 4; Social workers – 2; Speech therapists/path ologists – 2; Community	BS – 31 UCS – 29 PCSS – 18 RS – 8 CS – 8 DI – 8 IC – 7 IKI – 7 UD – 7 GS – 5 RD – 4 FS – 3 SE – 1 SH – 1	Group – 19, Individual – 2, Both – 13, Not stated – 3	Total (calculating the average when there is a range given for a group) – 121/17 = 7.1, Median – 6 people  Calculating the high and low range – 110	Total (calculating average when there is a range given for a group) = 363.63/24 = AVE 15.2 hours Median – 12 hours  Not stated (or not given in

	Jordan – 1 Greece – 1 New Zealand – 1 Canada – 1 France – 1 Tanzania – 1 Croatia, Cyprus, Former Yugoslavian Republic of Macedonia – 1 United Arab Emirates – 1			nurses – 2; Other – 8; Not stated – 12	Not stated – 1		– 132. Ave – 6.5 – 7.7.  Not stated/ Individual – 20	hours) -13
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**Key for Table 3.2**

**Modalities of delivery**

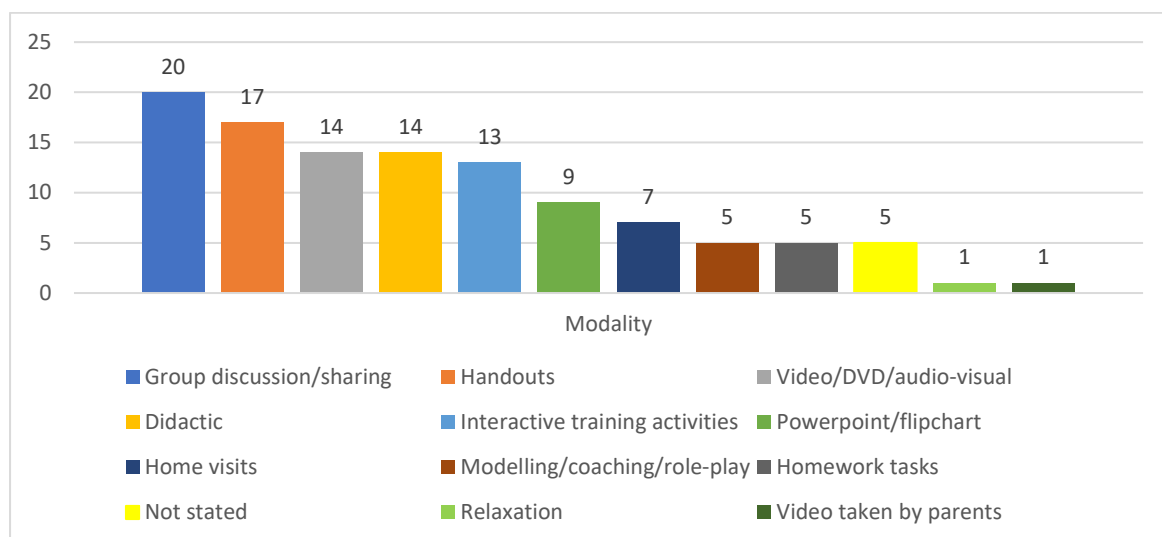
Av = Video/Audio-visual/DVD; D = Didactic; E = written Educational material/handouts; G = Group discussion; I = Interactive/training activities; H = Homework tasks; Hv = Home visits; M = modelling/coaching/demonstration/role play; P = Powerpoint/flipchart; Pv = Video taken by parents; R = Relaxation exercises; NA = Not applicable

**Objectives of intervention**

BS – Positive behaviour support principles and strategies to manage/reduce difficult behaviours; CS – Imparting effective coping skills for parents; DI – Decreasing isolation by encouraging parents to provide informal support to each other; FS – Providing/discussing family support; GS – Planning and setting goals; UCS – Understanding child’s communication; socialisation or behaviour difficulties; IC – Improving confidence/empowerment; IKI – Increasing participants knowledge of available ASD interventions or support services; PCSS – Providing communication, socialisation or play strategies; RD – Discussing/managing reactions to diagnoses of ASD; RS – Reducing caregiver stress/anxiety/mental ill health; SE – Improving carer self-efficacy; SH – Improving cooperation between school and home; UD – Understanding the child’s developmental level

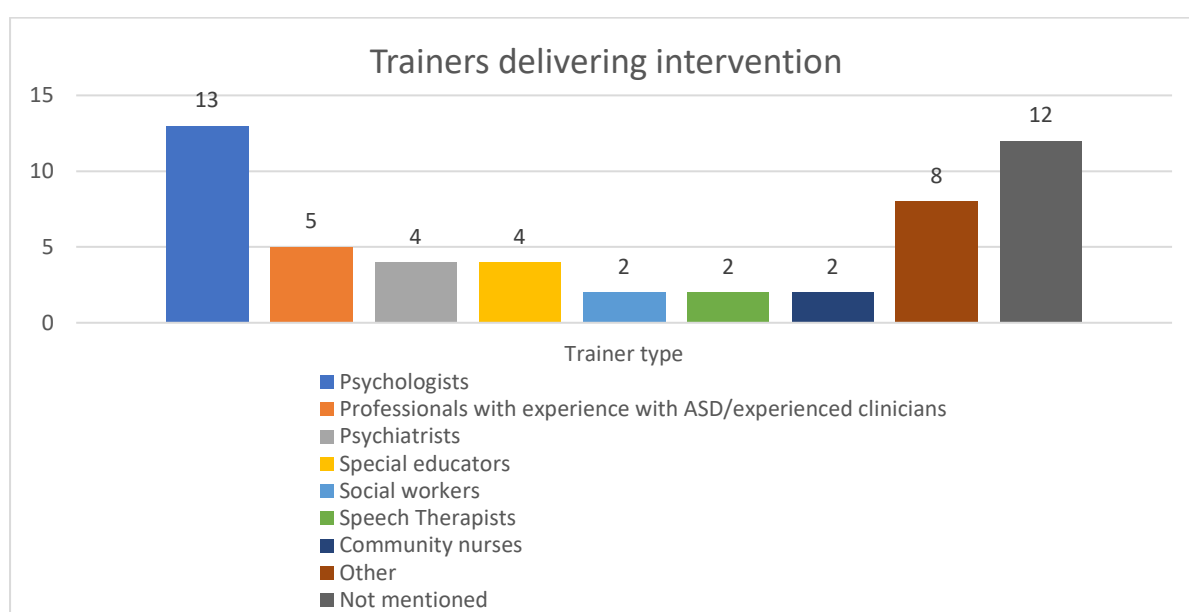
The 37 studies included in the review represented 20 countries and 34 unique programmes across all continents, with the exception of South America. Three of the countries (15%) were either LMIC or Low Income (India, Bangladesh and Tanzania), while the rest (85%) were either High-Middle-Income or HIC. Six countries had more than one publication included – Australia (9/37, 24.3.6%); UK (8/37, 21.6%); China (3/37, 8.19%); Turkey (2/37, 5.4%); Iran (2/37, 5.4%) and Japan (2/37, 5.4%). Other countries included Bangladesh; Canada; Croatia, Cyprus & Former Yugoslavian Republic of Macedonia (one joint publication); France; Greece; India; Republic of Ireland; Jordan; New Zealand; Tanzania and the United Arab Emirates.

Almost half of the PET programmes were delivered in urban areas (17/37, 45.9%), five were in both rural and urban areas (5/37, 13.5%) and only two were exclusively in rural areas (2/37, 5.4%). Thirteen publications did not report on location (13/37, 35.1%). The programmes were delivered using a range of modalities, including interactive training activities, group discussion/sharing and video/DVD/audio-visual. The different types of modalities are reflected in Figure 3.2 with the number of programmes that used the varying modalities indicated. The most commonly used modalities of PET delivery were group discussions (20/37, 54.1%); handouts (17/37, 45.9%); didactic methods (14/37, 37.8%) and video/DVD/audio-visual aids (14/37, 37.8%).



**Figure 3.2. Modalities of PET programme delivery (n= 37)**

As shown in Figure 3.3, PET programmes were delivered by a range of practitioners. Psychologists were the most commonly named professionals (13/37, 35.1%) followed by professionals with expertise in ASD (5/37, 13.5%). Interestingly, no publication listed parents/carers or other non-professionals as facilitators/trainers. The 'other' group reflected in the figure included a range of roles, e.g., 'interpreter', 'degree in Psychology' or 'student social worker' that did not easily fit into any of the other categories. Twelve publications did not provide details about trainers/facilitators (12/37, 32.4%).



**Figure 3.3. Types of trainers delivering PET programmes (n=37)**

PET programmes often included multiple goals or objectives. The majority of programmes (31/37, 83.8%) sought to provide parents with positive behavioural principles and strategies to manage or reduce behavioural difficulties. The next most commonly cited goal was to provide communication, socialisation or play strategies to parents. One of the publications did not state the goals of the intervention. The goals of the interventions and how many times they were stated are detailed in Table 3.3.

**Table 3.3. Stated goals and objectives of PET programmes (n=37)**

<b>Stated goal and objective</b>	<b>Number of programmes</b>
Positive behaviour support principles and strategies to manage/reduce difficult behaviours	31 (83.8%)
Help parents understand their child's communication/socialisation or behavioural difficulties in relation to ASD	29 (78.4%)
Provide communication, socialisation or play strategies to parents	18 (48.6%)
Reduce parental stress, anxiety or improve parental mental health	8 (21.6%)
Provide parents with effective coping skills to improve their quality of life	8 (21.6%)
Decrease parental isolation by encouraging them to provide informal support to each other	8 (21.6%)
Improve parental confidence or encourage empowerment	7 (18.9%)
Help parents understand their child's developmental level in the context of ASD	7 (18.9%)
Increase parental knowledge of support services or available interventions	7 (18.9%)
Goal setting for parents	5 (13.5%)
Discuss or help parents manage their reactions to the diagnosis of ASD	4 (10.8%)
Understand and provide support to family and community responses to the diagnosis of ASD	3 (8.1%)
Improve relationships between school and home	1 (2.7%)
Provide parents with emotional regulation strategies for their child	1 (2.7%)
Improve parental self-efficacy	1 (2.7%)

The duration of PET programmes ranged from 90 minutes to 30 hours, with an average time (where time was provided) of 16.15 hours and a mean of 12 hours. Thirteen publications (13/37, 35.1%) did not comment on the duration of their sessions. Nineteen PET programmes were group-based (19/37, 51.4%), 13 included a mixture of group and individual work (13/37, 35.1%) and only 2 were exclusively individual (2/37, 5.4%) (Stuttard et al., 2014; Tellegen & Sander, 2014). Of the 17 publications that commented on numbers of parent/carer participants attending group-based programmes, ranges were typically given (e.g. between 5 and 16 people). The average range per group was between 6.5 and 7.7, with a mean of the group size of 6.

### *3.3.2 Research methodologies and evidence-base for PET programmes*

Table 3.4 summarises details of research methods used and evidence-base generated for the PET programmes included in the review.

**Table 3.4. Research methodologies and evidence-base for PET programmes**

<b>First author (year)</b>	<b>Study design (Randomised Controlled Trial (RCT); Single subject; Quasi-experimental; Qualitative; Descriptive; Survey)</b>	<b>Outcome measures</b>	<b>Goal of evaluative research (Feasibility; Parent outcomes; Child outcomes)</b>	<b>Results</b>	<b>Participant numbers (n)</b>	<b>Quality appraisal (%)</b>
<b>Shields (2001)</b>	Descriptive	N/A	None (descriptive)	None	N/S (programme description)	N/A
<b>Sofronoff (2002)</b>	Quasi-experimental	Parental self-efficacy in the management of Asperger's syndrome; Eyberg Child Behaviour Inventory (ECBI)	Parent outcomes; Child outcomes	Positive	89	75
<b>Mukaddes (2004)</b>	Quasi-experimental	Ankara developmental screening inventory	Child outcomes	Positive	21	50
<b>Tonge (2006)</b>	RCT	General health questionnaire; Parenting Stress Thermometer; FAD; DBC	Parent outcomes	Positive	103	75

<b>Yucel (2007)</b>	Quasi-experimental	Parent information form and knowledge test (purpose-designed for study)	Feasibility; Parent outcomes	Positive	72	75
<b>Birkin (2008)</b>	Qualitative	Semi-structured	Feasibility	None	89	100
<b>Wang (2008)</b>	Quasi-experimental	Maternal behaviour rating scale	Parent outcomes	Positive	27	75
<b>Whittingham (2008)</b>	RCT	ECBI; Parenting scale; Being a parent scale	Feasibility; Parent outcomes	Positive	59	75
<b>Keen (2010)</b>	Quasi-experimental	Parenting Stress Index – SF (PSI-SF); Parenting sense of competence scales; Communication and symbolic behaviour scales development profile; Mullen scales of early learning	Parent outcomes; Child outcomes	Positive	39	100
<b>Mulligan (2010)</b>	Qualitative	Focus group	Feasibility	Positive	13	100
<b>Roberts (2010)</b>	Quasi-experimental	ECBI; GHQ; Child's social anxiety (social worries questionnaire); Child's social communication profile (Australian scale); Qualitative feedback	Feasibility; Parent outcomes; Child outcomes	Positive	8	50
<b>Halpin (2011)</b>	Not stated	Not stated	Not stated	None	Not stated	N/A

<b>Murphy (2011)</b>	Quasi-experimental	Customised questionnaire to assess self-reported knowledge and confidence	Feasibility; Parent outcomes; Child outcomes	Mixed	28	25
<b>Okuno (2011)</b>	Quasi-experimental	Confidence degree for families; CBCL	Parent outcomes; Child outcomes	Positive	14	50
<b>Papavasiliou (2011)</b>	Quasi-experimental	CARS; Short sensory profile	Child outcomes	Positive	40	25
<b>Pillay (2011)</b>	Quasi-experimental	DBC; Parental knowledge questionnaires; Parent satisfaction questionnaire	Feasibility; Parent outcomes; child outcomes	Positive	79	25
<b>Samadi (2012)</b>	Qualitative	Parents asked to write down their thoughts about the kit and applicability	Feasibility	Positive	39	100
<b>Al-Khalaf (2013)</b>	Quasi-experimental	Coping Strategy Indicator, PSI-SF	Feasibility; Parent outcomes	Positive	20	75
<b>Connolly (2013)</b>	Qualitative	Parent education group post-programme questionnaire	Parent outcomes	Positive	5	100
<b>Farmer (2013)</b>	Quasi-experimental	Self-constructed pre/post questionnaire (knowledge, what participants had learned, most	Feasibility; Parent outcomes	Positive	86	50

		helpful parts of the course)				
<b>Samadi (2013)</b>	Quasi-experimental	General Health Questionnaire (GHQ); Coping Styles Questionnaire; Parenting Stress Index – SF (PSI-SF)	Feasibility; Parent outcomes	Positive	37	50
<b>Cutress (2014)</b>	Quasi-experimental	Post-programme questionnaires	Feasibility	Positive	120	25
<b>Ji (2014)</b>	Quasi-experimental	Health related quality of life McMaster family assessment device (FAD), Simplified coping style questionnaire; Multidimensional scale of perceived social support; Caregiver burden of index; Childhood autism rating scale (CARS); General self-efficacy	Parent outcomes	Positive	42	100
<b>Stuttard (2014)</b>	Quasi-experimental	ECBI; Parenting sense of competence scale; parent identified child behaviour goal	Feasibility; Parent outcomes; Child outcomes	Positive	76	75

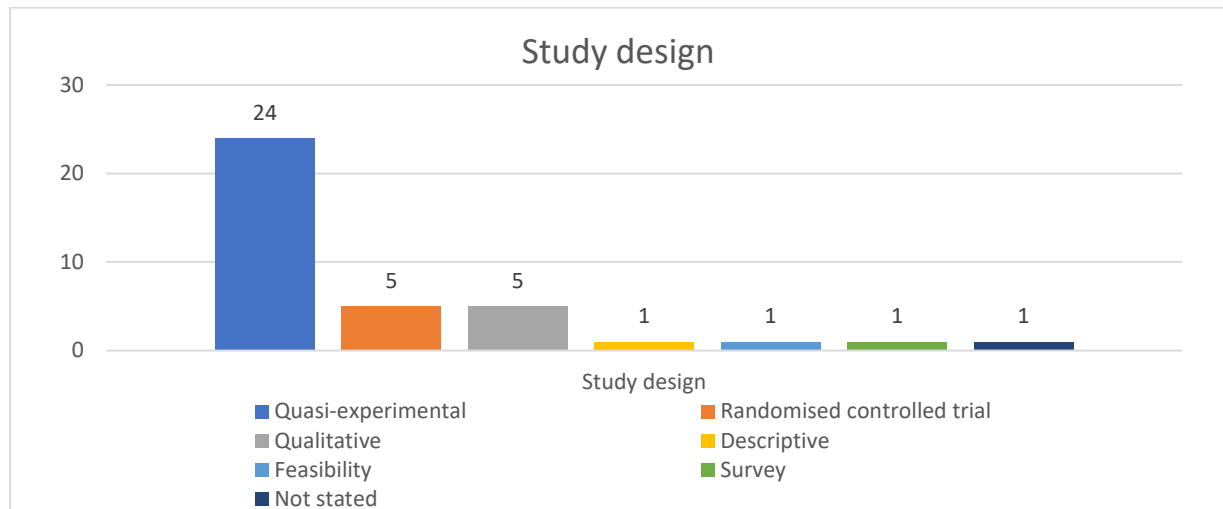
<b>Tellegen (2014)</b>	RCT	Family background questionnaire; ECBI; Parenting Scale; Parenting task scale' Depression and Anxiety and Stress scales; Family observation schedule; Parent problem checklist; Relationship quality index; Goal achievement scales; Client satisfaction questionnaire; Therapy attitude inventory	Feasibility; Parent outcomes; Child outcomes	Positive	64	75
<b>Tonge (2014)</b>	RCT	Vineland Adaptive Behaviour Scales (VABS); Developmental Behaviour Checklist – ASA (DBC).	Child outcomes	Positive	105	75
<b>Gaad (2015)</b>	Quasi-experimental	Pre, during and post intervention questionnaire (type not specified)	Parent outcomes	Positive	33	33
<b>Grahame (2015)</b>	RCT	Clinical global impressions.	Feasibility; Parent outcomes;	Positive	43 (families)	100

			Child outcomes			
<b>Patra (2015)</b>	Quasi-experimental	Indian scale for assessment of Autism; Gesell drawing test; Vineland social and maturity scale; Malin Intelligence test for Indian children; Ravens Coloured Progressive Matrices; Family interview for stress and coping in mental retardation; Parental knowledge of ASD questionnaire	Feasibility; Parent outcomes	Positive	18	75
<b>Yu (2015)</b>	Quasi-experimental	Children's sleep habits questionnaire; Family inventory of sleep habits; Child behaviour checklist; Parental concerns questionnaire; Pittsburg sleep quality index; PSI-SF	Parent outcomes; Child outcomes	Positive	50 families	50
<b>Gaad (2016)</b>	Quasi-experimental	Pre, during and post intervention	Parent outcomes	Positive	33	33

		questionnaire (type not specified)				
<b>Harrison (2016)</b>	Quasi-experimental	Qualitative autism knowledge assessment, modified therapy inventory (for acceptability)	Feasibility	Positive	41	100
<b>Kazuteru (2016)</b>	Quasi-experimental	WHO Quality of Life 26, PSI-Sf	Feasibility; Parent outcomes	Positive	24	50
<b>Stuttard (2016)</b>	Quasi-experimental	ECBI; Parenting sense of competence scale	Feasibility; Parent outcomes; Child outcomes	Positive	67	100
<b>Tolmie (2016)</b>	Quasi-experimental	Family confidence Scale	Feasibility; Parent outcomes	Positive	135	50
<b>Blake (2017)</b>	Qualitative	10 open-question format interviews	Feasibility	Positive	10 families	50
<b>Ilga (2017)</b>	Quasi-experimental	Social validity measure; Treatment evaluation inventory; Therapy attitude inventory; Likert style questions on programme satisfaction; French Beck Depression – SF, French	Feasibility; Parent outcomes; Child outcomes	Mixed	28	50

		parenting stress index; Beach centre family quality of life scale; ASD behaviour problems for children; VABS				
<b>Preece (2017)</b>	Survey	Structured survey designed for research	Feasibility	Positive	148	100
<b>Summary</b>	RCT-5; Single Subject - 0; Quasi-experimental -24; Qualitative - 5; Survey - 1; Descriptive - 1; Not stated - 1	Total measures used - 61 Measurement focus: Child development - 8; Parental Knowledge of ASD - 6; Parental self-efficacy/confidence - 6; Parenting support measures - 5; Parental Anxiety/stress/mental health - 5; Coping style/strategies - 5; Quality of life - 3; Child behaviour - 5 Target population of measures: Parents - 34 Child - 22 Family - 5	Feasibility - 23; Parent outcomes - 24; Child outcomes - 14; Not stated - 1; Descriptive - 1	Positive - 32 Mixed - 2 Negative - 0 Not stated - 3	Total n = 1841 individuals = AVE - 57.1 ; Median - 41.5; 3 - report families (43, 10, 50); Descriptive - 1; Not stated - 1	Total - 2383/34 = 70.1% Median = 75%  25% - 4 33% - 1 50% - 10 75% - 10 100% - 10 N/A - 2

Six different types of study designs were identified. The most common, quasi-experimental was used in 24/37 (64.8%) of the studies. No single-subject designs were identified. The range and frequency of study designs are shown in Figure 3.4.



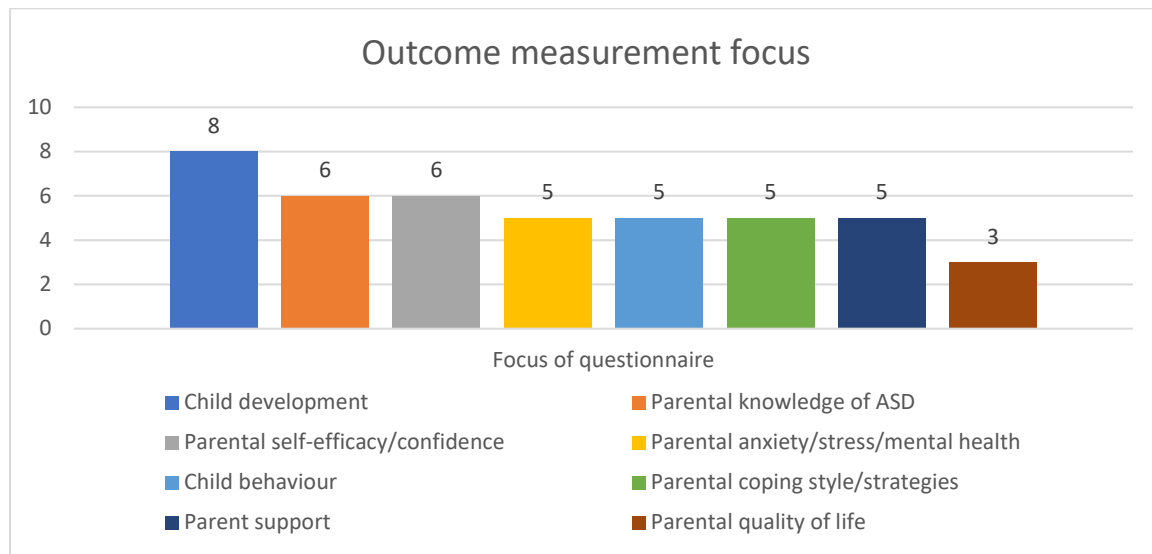
**Figure 3.4: Study design of PET studies in the review (n= 37)**

Thirty-two publications (86.5%) provided data on sample size with an average of  $n = 57.156.3$  and a median  $n = 41.5$ . Sample sizes ranged from 5 to 148. Three publications reported on how many families, rather than individuals, participated in their study (40, 10 and 50 families were reported in those studies (Grahame et al., 2015; Blake et al., 2017; Yu et al., 2015)).

A broad range of outcome measures were used in the research. In total, 61 different measures were identified with only 14 (23%) used in more than one study. The most commonly used outcomes measures were the Eyberg Child Behaviour Inventory (Eyberg & Pinkus, 1999; Sofronoff & Farbotko, 2002; Whittingham et al., 2008; Roberts & Pickering, 2010; Stuttard et al., 2014; Tellegen & Sander, 2014; Stuttard et al., 2016) and the Parenting Stress Index – Short Form (Abidin, 1995; Keen et al., 2010; Al-Khalaf, Dempsey & Dally, 2013; Samadi, McConkey, Kelly, 2013; Yu et al., 2015; Kazuteru et al., 2016), both used in (6/37) of studies. Three other measures, the Parenting Sense of Competence (Johnston & Marsh, 1989; Keen et al., 2010; Stuttard et al., 2014; Stuttard et al., 2016), Developmental Behaviour Checklist (Einfeld & Tonge, 1992; Tonge et al., 2006; Pillay et al., 2011; Tonge et al., 2014) and the General Health Questionnaire (Goldberg & Hillier, 1979; Tonge et al., 2006; Roberts &

Pickering, 2010; Samadi, McConkey, Kelly, 2013) were used three times. The majority of questionnaires (47/61, 77%) were only used once.

Outcome measures focused on parent support; coping style/strategies; quality of life; knowledge and child development, amongst others. Figure 3.5 shows the number of publications per specific outcome measurement focus.



**Figure 3.5. The focus of outcome measurement in PET studies (n=37)**

The outcome measures targeted three different groups, i.e. parents/carers, children, and families. Thirty-four measures (34/61, 55.7%) focused on parents, 22 on child changes (22/61, 36%) and 5 on family outcomes (5/61, 8.2%).

Thirty-two of the PET programmes (32/37, 86.4%) reported positive results, two reported both positive and negative results (2/37, 5.4%) (Murphy et al., 2011; Ilg et al., 2017), and three did not report any results (3/37, 8.1%) (Shields, 2001; Birkin et al., 2008; Halpin, Pitt, Dodd, 2011). No publications reported only negative results. Positive results in this case referred to changes that the PET programme hoped to change (e.g. reduction in stress, increased knowledge).

Results from the MMAT, used to appraise the publications, indicated that the average score was 70.1%. Ten of the publications were rated as 100%, 10 as 75% and 10 as 50%. One was rated as 33% (Gaad & Thabet, 2016) and 4 at 25% (Murphy et al., 2011; Papavasiliou et al., 2011; Pillay et al., 2011; Cutress & Muncer, 2014).

### *3.3.3 Implementation factors relevant to the PET programmes*

A range of factors may be relevant to implementation in different settings. Here we extracted data on measurement of trainer fidelity, manualisation of programmes, consideration of cultural appropriateness in programmes, and multi-cultural use of programmes. Table 3.5 shows a summary of all implementation-related factors identified in the included publications.

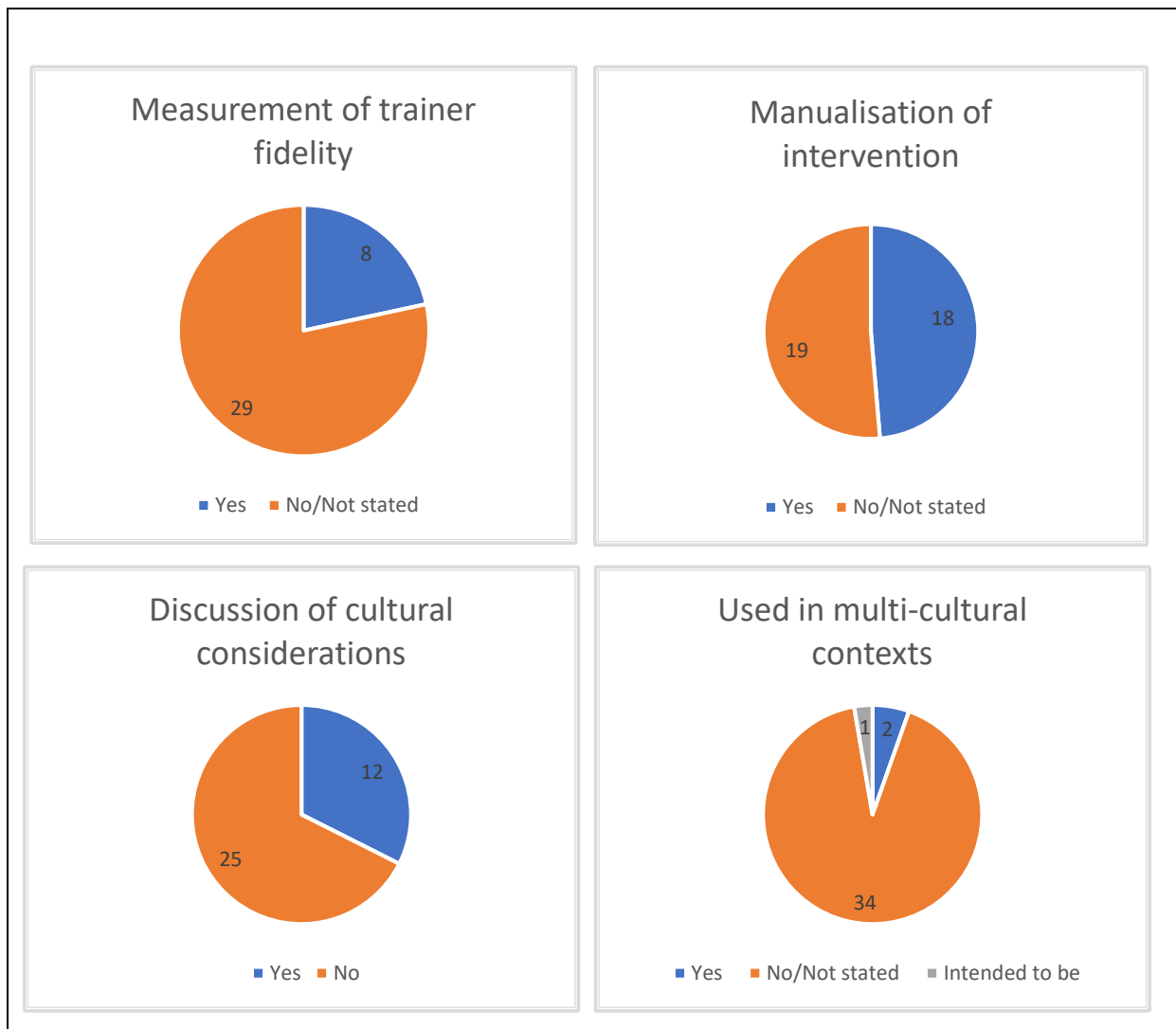
**Table 3.5. Implementation factors related to PET programmes**

<b>First author (year)</b>	<b>Manualisation</b>	<b>Trainer fidelity</b>	<b>Cost to provider</b>	<b>Cost to participant</b>	<b>Cultural appropriateness discussed</b>	<b>Used in multi-cultural context</b>
<b>Shields (2001)</b>	YES	Not stated	Not stated	Not stated	YES	Not stated
<b>Sofronoff (2002)</b>	YES	Not stated	Not stated	Not stated	NO	NO
<b>Mukaddes (2004)</b>	Not stated	Not stated	Not stated	Not stated	NO	NO
<b>Tonge (2006)</b>	Not stated	Not stated	Not stated	Not stated	NO	NO
<b>Yucel (2007)</b>	Not stated	Not stated	Not stated	Not stated	NO	YES
<b>Birkin (2008)</b>	NA	Not stated	Not stated	Not stated	YES	NO (but targeted different populations within New Zealand)
<b>Wang (2008)</b>	Not stated	Not stated	Not stated	Not stated	YES	NO
<b>Whittingham (2008)</b>	YES	Trained but no assessment	Not stated	Not stated	NO	NO
<b>Keen (2010)</b>	YES	Meeting with the author	Not stated	Not stated	NO	NO
<b>Mulligan (2010)</b>	YES	Not stated	Not stated	Not stated	NO	NO
<b>Roberts (2010)</b>	YES	YES	Not stated	Not stated	NO	NO
<b>Halpin (2011)</b>	Not stated	Not stated	Not stated	Not stated	NO	NO
<b>Murphy (2011)</b>	YES	Not stated	Not stated	Not stated	NO	NO
<b>Okuno (2011)</b>	Not stated	Not stated	Not stated	Not stated	NO	NO
<b>Papavasiliou (2011)</b>	Not stated	Not stated	Not stated	Not stated	NO	NO
<b>Pillay (2011)</b>	YES	Not stated	Not stated	Not stated	NO	NO
<b>Samadi (2012)</b>	YES	YES	Not stated	Not stated	NO	NO

<b>Al-Khalaf (2013)</b>	Not stated	Not stated	Not stated	Not stated	YES	NO
<b>Connolly (2013)</b>	Not stated	Not stated	Not stated	Not stated	NO	Not stated
<b>Cutress (2013)</b>	YES	Not stated	Not stated	Not stated	NO	Not stated
<b>Farmer (2013)</b>	YES	Not stated	Not stated	Not stated	NO	NO
<b>Samadi (2013)</b>	Not stated	Not stated	Not stated	Not stated	YES	NO
<b>Ji (2014)</b>	Not stated	Not stated	Not stated	Not stated	NO	NO
<b>Stuttard (2014)</b>	YES	YES	Mean cost of GBP 3225 to deliver intervention, staff time accounted for greatest proportion of cost	Not stated	YES	Not stated
<b>Tellegen (2014)</b>	YES	YES	Not stated	Not stated	YES	Not stated
<b>Tonge (2014)</b>	YES	Not stated	Not stated	Not stated	NO	NO
<b>Grahame (2015)</b>	YES	YES	Not stated	Not stated	NO	NO
<b>Patra (2015)</b>	Not stated	NO	Not stated	Not stated	NO	Not stated
<b>Yu (2015)</b>	YES	Not stated	Not stated	Not stated	NO	NO
<b>Gaad (2016)</b>	Not Stated	Not stated	Not stated	Not stated	YES	NO
<b>Harrison (2016)</b>	Not stated	Not stated	Not stated	Not stated	YES	NO
<b>Kazuteru (2016)</b>	Not stated	Not stated	Not stated	Free	NO	NO
<b>Stuttard (2016)</b>	YES	YES	Mean cost of GBP 2390 to deliver intervention, staff time accounted for greatest proportion of cost	Not stated	NO	Not stated

<b>Tolmie (2016)</b>	Not stated	Not stated	Not stated	Free	NO	Not stated
<b>Blake (2017)</b>	Not stated	Not stated	Not stated	Not stated	YES	YES
<b>Ilga (2017)</b>	YES	Not stated	Not stated	Free	YES	NO
<b>Preece (2017)</b>	Not stated	Not stated	Not stated	Not stated	YES	Intended to be when developed
<b>Summary</b>	YES – 18 NO/not stated – 19	YES – 8 NO/Not stated – 29	Reported cost to provider – 2 Not stated – 35	Free – 3 Not stated – 34	YES – 12 NO – 25	YES – 2 Not stated – 8 NO – 26 Intended to be – 1

As shown in Figure 3.6 trainer fidelity was commented on in 8/37 (21.6%) of programmes, and manualisation was reported in 18/37 (48.6%). Cultural appropriateness comments were included in 12/37 (32.4%) of studies. Only 2/37 (5.4%) of the programmes had been delivered in multi-cultural contexts (Yucel & Cavkautar, 2007; Blake et al., 2017) and a further one was designed for future multi-cultural use (Preece et al., 2017).



**Figure 3.6.** Measurement of trainer fidelity, manualisation of intervention, discussion or comment on cultural factors and use of PET programmes in multi-cultural contexts (n= 37)

PET programme costs were described in only 2 of the studies (5.4%) (Stuttard et al., 2014; Stuttard et al., 2016). The programmes reported mean costs of GBP3225 and GBP2390 respectively (Stuttard et al., 2014; Stuttard et al., 2016) of which it was commented that staff

time had accounted for the greatest proportion. Regarding cost to participants, only three publications (3/37, 8.1%) stated that the programme was free to participants (Birkin et al., 2008; Tolmie, Bruck, Karlake, 2016; Preece et al., 2017). None of the other studies indicated the financial impact of participation on parents/carers.

### **3.4 Discussion**

Given the importance of parent empowerment through education and training, post-diagnostic programmes for ASD are globally recommended. However, recent reviews suggested that the evidence-base for parent education and training (PET) programmes may be limited. We therefore set out to perform a rigorous scoping review to describe the characteristics of all non-USA-based PET programmes in the ASD literature, to review the research methods and evidence-base for these programmes, and to determine to what extent factors relating to implementation of such PET programmes had been explored.

#### *3.4.1 Descriptive characteristics*

We identified 37 publications representing 34 unique PET programmes, which met the inclusion criteria for the study. Publications were from 20 countries, including all continents except South America. Whilst the PET programmes had the primary and broadly similar goal of providing knowledge and skills to parents, they were nonetheless very different in objectives; modalities of delivery; length; trainer backgrounds and group size. The two most commonly cited objectives were helping parents/carers understand their child's communication, socialisation or behaviour in relation to ASD (78.4%) and providing behavioural support strategies or principles to parent/carers (83.8%). Objectives, however also included a range of other goals including teaching communication/socialisation strategies (48.6%), reducing parental stress/anxiety/mental health concerns (21.6%), and decreasing parental isolation by encouraging informal support between parents (21.6%). These observations suggest that PET programmes see the relatively discreet aim of providing knowledge about ASD to parents as only one of their functions, and maps onto our earlier comment that many PET programmes are in fact hybrid programmes straddling parent support (either psychoeducation or care coordination) and parent-mediated intervention (for

core ASD symptoms or maladaptive behaviours) (see chapter 2). We propose that the term PET may therefore be a helpful way to group such programmes.

One of the striking findings of this scoping review was the great variability in programme structure, modalities, trainers and duration. The majority of programmes were group-based and used group discussions as a prominent part of the PET. Groups were typically small, included 12-24 hours of face-to-face time, and were usually facilitated by healthcare providers, mainly psychologists and psychiatrists. It was interesting that no PET programmes were led by parents or other non-professionally individuals. Hamdani et al., (2015) though not included in the reviewed publications, provided an interesting example where non-specialist 'champion parents' were as trainers in Pakistan. We suggest this may be a reflection of the fact that the majority of studies were performed in higher-resourced settings. In most Low- and Middle-Income Countries (LMIC) capacity and cost may make it very difficult for mental health professionals to lead PET programmes. There is therefore a clear need to develop and evaluate PET programmes that can be delivered by lower-qualified, but skilled facilitators. The World Health Organization / Autism Speaks Caregiver skills training (CST) (WHO, 2013; WHO, 2015) may become a good example of such a PET programme.

#### *3.4.2 Research methodology used and evidence-base of PET programmes*

In a pattern similar to the recent review of EarlyBird/EarlyBirdPlus (EB/EBP), the majority (64.8%) of studies used a quasi-experimental study designs and only 5 randomised controlled trials were identified. Sample size was relatively modest with a mean  $n = 41.5$  and one third of studies had fewer than 30 participants. A wide range of outcome measures (including parent, child and family outcomes) were used, with only a handful of standardised measures (e.g. Eyberg Child Behaviour Inventory and Parental Stress Index) used in more than one study. The significant methodological variability therefore makes it very difficult to make direct comparisons of PET programmes. As highlighted in the EB/EBP review (Dawson-Squibb, Davids & de Vries, in press; Chapter 2), there are no universally-accepted evaluation frameworks that might allow for the summarising and comparison of PET programmes. Such observations therefore make it hard to interpret the 'positive' results of 86.4% of PET programmes. Whilst these findings are in line with the USA-based review of Schultz and colleagues (2011), it is difficult to judge the robustness of such conclusions. For instance, the

absence of almost any negative results raises the question about publication bias, if nothing else. The absence of randomised or contrast groups makes it difficult to know whether positive results were attributable to any 'active ingredients' or simply to the provision of networking between families on a similar post-diagnostic journey. In addition, the appraisal of the methodological quality of the publications indicates that, while some portion of the studies (27%) meet 100% for basic quality standards, the remainder (73%) does not. This suggests that further improvement in methodological design is required to limit possible bias and interpret results with confidence.

### *3.4.3 Factors of relevance to the implementation of PET programmes*

Autism Spectrum Disorder (ASD) is a global phenomenon and PET programmes are therefore required across the globe. Factors relating to the implementation of such programmes are therefore important. Interestingly, the majority of PET programmes examined here were conducted in urban areas and only a small portion commented on facilitator/therapist fidelity (the consistency with which programmes were delivered in the manner intended). Half of PET programmes had been manualised, but only a third specifically commented on cultural acceptability and on the appropriateness of the PET for multi-cultural participants. This observation maps well onto the recommendation by Preece and Trajkovski (2017) that further research is needed to investigate how cultural differences can be addressed in local PET programmes.

Many other factors, including cost, may influence implementation. Only two studies commented on cost, most of which was attributed to staff costs (Stuttard et al., 2014; Stuttard et al., 2016), a finding very similar to previous reviews (Shattuck & Grosse, 2007; Birkin, 2008; Chiri & Warfield, 2012; Gillespie-Lynch, Brezis, 2017). An intervention with staff cost in the region of GBP 2000 – 3000 is likely to be unaffordable in most LMIC, underlining the potential value of parents or other lower-qualified facilitators for PET.

While this review focused on existing ASD interventions, there is much to be learned about implementation research from the developing literature in related fields done in low resource settings. Global mental health research focused on interventions in sub-Saharan African settings along with research in intellectual disability and community-based rehabilitation

interventions in LMIC are increasingly attentive towards implementation, dissemination and related factors currently left out of the majority of research in ASD PET related work (Nakumuli-Mpunga et al. 2014; Lemmi et al., 2015; Singla et al, 2015; Kouimtsidis et al., 2017). Much of this literature focuses on the evaluation and feasibility of interventions and specifically incorporates participatory methodologies. Similar to what has been found in this review there is a heterogeneity of interventions and limited good-quality evidence on them reported in other research fields (Lemmi et al., 2015). The research solutions they are finding may be of benefit to those examining PET.

#### *3.4.4 Limitations*

We acknowledge a number of limitations of this review. Firstly, we opted to not include grey literature which may have revealed additional sources of relevant PET research. However, we were specifically interested in high-quality, peer-reviewed studies to get a broad sense of the PET research landscape to date. We also acknowledge some subjectivity in the data extraction and abstraction process. However, as outlined in the methods, we took great care to be systematic; to include a minimum of two raters per step and to have a consensus procedure in place. Attempts to limit this potential bias were made through inter-rater reliability testing and consensus before and during the review process. A limitation of the last comprehensive review in the area of PET by Schultz, Schmidt & Stitche (2011) was the restriction of scope only on USA-derived publications. We acknowledge that our deliberate exclusion of USA-based studies may also have introduced a limitation. However, the review presented here is the most comprehensive examination of PET programmes outside the USA to date.

### **3.5 Conclusion**

The recent scoping review of EarlyBird and EarlyBirdPlus, two PET programmes from the UK (Dawson-Squibb, Davids & de Vries, in press), raised the question whether the low-level of evidence found for EB/EBP was a reflection on the specific programmes or an indication of the state of research for the broader field of PET programmes. This broader review identified 37 programmes (including four EB/EBP studies) from all continents apart from South America. Studies were highly variable in characteristics, in research methods and in outcome measures

used for efficacy-testing. Overall, very limited robust conclusions can therefore be drawn about the efficacy of PET programmes to date. The review also identified relatively few studies that expressly considered other factors that may be of importance in the implementation of PET, such as cultural appropriateness, trainer fidelity, manualisation and cost. As highlighted by Dawson-Squibb, Davids & de Vries (in press), the lack of any PET evaluation framework adds to the challenge of systematic comparisons of the suitability of PET programmes for specific settings. Further research in all these aspects of PET programmes will be invaluable to empower families who live with ASD around the globe.

### **3.6 Chapter summary**

Empowering families of children with ASD through education and training is regarded as best practice. A wide range of Parent Education & Training (PET) programmes are delivered around the globe, but there was limited knowledge about the characteristics, research methods and outcomes used to measure these programmes. It was also not clear how much PET research to date had evaluated factors of relevance to implementation. We therefore performed a scoping review of all peer-reviewed PET publications outside the USA. A search was conducted between March and May 2017 EBSCOhost, Sabinet, SAGE Journals, Directory of Open Access Journals, BioMed Central, Scopus, and Science Direct. Two reviewers independently screened titles and abstracts for inclusion. Four reviewers extracted data, focusing on descriptive characteristics of PET programmes, research methodologies and evidence base, and if implementation factors had been explored. Reviewers also performed a mixed-methods quality appraisal of publications. A total of 37 publications representing 34 unique programmes were identified. Publications described a highly diverse range of Pet programmes across 20 countries and all continents except South America. Programmes varies significantly in their goals, modalities, length but the majority were group-based. Quasi-experimental studies were the predominant research design, and a broad range of outcome measures, rarely used in more than one study, was found. The majority of studies (32/37, 86.4%) reported positive outcomes in relation to the core study objectives and only 2 studies reported some negative findings. Quality appraisal rated only 10/37 (27%%) of studies to have

met all the methodological quality criteria. Factors relevant to implementation such as manualisation, fidelity and cost were commented on infrequently.

In spite of the clear need for ASD PET programmes, the current global research evidence-base is relatively small, predominantly in high-income countries, and focused on urban populations, with highly-skilled clinicians as facilitators. In addition, the quality of research has been variable, there is lack of consensus on outcome-measures, and little evidence of broader factors that may influence implementation of PET programmes. We strongly recommend joined-up, global efforts to expand the evidence-base of this vital aspect of ASD practice.

# Chapter 4

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## **Developing an evaluation framework for Parent Education & Training in Autism Spectrum Disorder: results of a multi-stakeholder process**

Dawson-Squibb, J.J. & de Vries, P.J. Submitted to *BMC Implementation Science*

### **4.1 Introduction**

The consensus of recent studies in the USA, Europe and in other parts of the world indicates a prevalence rate for Autism Spectrum Disorders (ASD) in the region of 1% (Durkin et al., 2010; Elsabbagh et al., 2012; Hansen, Schendel, Parner, 2015; Christensen et al., 2016). Given this high prevalence, the World Health Organization (WHO) has declared ASD to be a global public health concern that requires appropriate prioritisation in member countries (WHO, 2014).

The WHO resolution on ASD recommended that appropriate access to assessment and intervention should be made to families, emphasising and including psychoeducation to parents and carers (WHO, 2014). In addition, the resolution recommended contextually-relevant research on these aspects of ASD. The recommendation for psychoeducation and support to families is based on the fact that the level of need in ASD families represent some of the greatest burden of all disabilities (Cutress & Muncer, 2014). This type of parent support and intervention is therefore considered part of best practice, in particular, shortly after diagnosis, to form the foundation for future positive advocacy and empowerment of families.

‘Parent Training’ is a term used in the ASD literature to cover a range of interventions and supports that include parents (Aman et al., 2009; Beaudoin, Sebire & Couture, 2014; Oosterling et al., 2014). Bearss et al. (2015) provided a useful framework and taxonomy and suggested that parent training could be divided into two categories, i.e. ‘Parent Support’ and ‘Parent-Mediated Interventions’. Parent Support includes psychoeducation and care

coordination, where the parent/carer is the direct beneficiary, and the child with ASD the indirect beneficiary of the intervention. Parent-Mediated Interventions refer to intervention provided by parents to their children with ASD, with the child therefore being the direct beneficiary of the intervention. Parent-Mediated Interventions might target core features of ASD (e.g. joint attention; communication; imitation; turn-taking) or focus on maladaptive behaviours (e.g. disruptive behaviours, sleep, feeding or toileting difficulties). While parent-mediated interventions are increasingly the focus of research (Nevill, Lecavalier & Stratis, 2016; Green et al., 2017; Watson et al., 2017), the value of psychoeducation, in particular its comparative cost-effectiveness, has also been highlighted (Rund et al., 1994; Breitborde, Woods & Srihari, 2009).

To add a layer of complexity, many programmes have multiple goals which include both supporting parents/carers and providing them with education or skills. For this reason, such programmes might not fall exclusively into the Parent Support or Parent Mediated Intervention categories described by Bearss et al. (2015). In chapter 2 we acknowledged that many programmes may therefore be 'hybrids'. We therefore proposed to use the term 'Parent Education and Training' (PET) as a placeholder to refer to the programmes of interest in this thesis. We defined PET as the passing on of information or skills to parents using a range of modalities (didactic; role-play; discussions; video guidance) in a context where parents/carers and trained facilitators are the direct participants. The emphasis is on knowledge transfer to parents and they are considered the priority participants not the parent-child dyad or child, though that and the child could benefit indirectly (Dawson-Squibb, Davids, & de Vries, in press).

In chapter 2 we reviewed EarlyBird and EarlyBird Plus (EB/EBP), two widely-used UK-developed PET programmes, and identified 18 publications from peer-reviewed and grey literature. There was enthusiastic support for EB/EBP from participants, but the overall level of evidence was fairly low from a traditional outcomes-based evidence-based medicine perspective. For instance, no randomized controlled trials had ever been performed on EB/EBP. In addition, we identified relatively little evidence of research on other factors that may be important for implementation of EB/EBP, such integration, expansion or demand. In chapter 3 we proceeded to perform a broader review of peer-reviewed publications on PET

programmes outside the USA to describe the characteristics of programmes, the evidence-base and research methods used, and to examine implementation-related factors that had been studied. The 37 publications identified 34 unique programmes that varied widely in goals, modalities and duration, and outcomes measures used. Factors all of relevance to implementation such as manualisation, fidelity measurement or cost, were not often included in research. Strikingly, we were not able to identify any consensus evaluation frameworks that could guide selection of a PET programme to meet the needs in local settings.

Implementation science is described as a method of enquiry designed to assist investigators to determine whether interventions or methods can be implemented in real-world settings that may differ in a number of variables from the original setting (Damschroder et al., 2009). More recently the concept of 'scaling-out' has been introduced into the field of implementation science, detailing when evidence-based interventions are adapted to new populations or delivery systems (Aarons et al., 2017). This is differentiated from 'scaling-up' where the same intervention is broadened to reach a larger but similar population. The developers of the scaling-out concept suggested that gathering certain empirical evidence about a programme is essential to determine whether it could be successful in a different population (Aarons et al., 2017). Bammer (2005) has proposed that a key pillar of implementation science is participatory methods. This recognises that a range of stakeholders have contributions to make in decision-making and understanding an issue that would be critical when considering factors like scaling-out (Bammer, 2005). In line with this Dingfelder and Mandell (2011) have highlighted the importance of diffusion in ASD intervention and research. They emphasize how few efficacious treatments are adopted or implemented successfully in community settings. As a solution they have urged researchers to change their practices by collaborating with communities to ensure the adoption, implementation and maintenance of already developed interventions and in the development of new ones (Dingfelder and Mandell, 2011).

There is consensus that ASD specific PET programmes are both important and necessary (Schultz, Schmidt & Stitche, 2011; WHO, 2014; Bearss et al., 2015). Currently, the global ASD community has no standardised framework to decide how best to evaluate PET programmes

and determine which would be best for their setting. In this study we set out to develop an evaluation framework for ASD PET programmes using a multi-stakeholder participatory strategy and implementation science approach. We propose that an evaluation framework for ASD PET programmes could provide a comprehensive but simple tool to evaluate the suitability of specific programmes for specific settings. We anticipate that such an evaluation framework may be particularly valuable for programme selection and evaluation in low-resource environments such as in Low- and Middle-Income Countries (LMIC).

## **4.2 Methods**

### *4.2.1 Study design*

We used an implementation science approach to develop an evaluation framework using a multi-stakeholder participatory strategy.

### *4.2.2 Participants*

Participants were recruited from multi-professional stakeholder groups using purposive sampling. We set out to identify participants with expertise in clinical aspects of ASD (psychiatry; psychology; speech & language; occupational therapy), in education of ASD (special education sector), in social care of ASD (social workers, family care workers), and in implementation science and health systems research. We aimed to have representation from the Health, Education, Social Development, Academic and non-profit sectors and included parents/carers of individuals with ASD. We also prioritised participants with expertise in low-resource settings. We aimed to recruit a group of  $n > 10$ .

### *4.2.3 Procedures*

After appropriate ethical approvals from the University of Cape Town (HREC007/2016) participants were recruited and asked to provide informed consent for participation in a consensus-building stakeholder workshop.

A half-day workshop was held at the Division of Child and Adolescent Psychiatry, University of Cape Town, South Africa, where participants gathered and the format and purpose of the

proceedings was described by the lead author. Following this, participants were asked to consider individually what they deemed important characteristics of an ASD specific PET programme shortly after diagnosis in a low-resource setting. They were also asked what barriers, challenges or problems they would foresee with implementing and scaling up such a programme, and were asked to write down their responses individually in the first instance. Participants were next assigned to three smaller groups of 3 – 4 individuals each. They were divided into groups with a mix of professions and roles in each group. These groups were asked to discuss their individual responses and work towards establishing key themes. Each group nominated a scribe to collate their answers.

Two invited participants were not able to attend the main workshop. A separate meeting was therefore held by the lead author with these two participants. They were asked to complete the same questions given to the main group and a facilitated discussion between the two of them was conducted by the lead author, and data recorded.

Following the smaller group stage, all the stakeholders were assembled together. A facilitated discussion conducted by the lead author then allowed participants to give feedback both on their individual responses and the smaller group discussions and themes. The themes and discussion generated by the separate fourth group was fed back to the rest of the participants at this stage. During this final stage of the process participants were asked to work towards the generation of a consensus framework that could be used to evaluate ASD specific PET programmes. Through consensus discussions the participants developed a draft Evaluation Framework which all members present agreed upon. The draft Evaluation Framework was subsequently sent to participants after the meeting for comment and feedback to ensure a final consensus document.

Eleven months after the first workshop, a subset of experts who participated in the multi-stakeholder workshop participated in a follow-up workshop to review the framework. This workshop took place in the context of reviewing two ASD PET programmes (see chapter 5). The comments and criticisms of the draft Evaluation Framework were discussed and consensus on a final framework was reached.

#### *4.2.4 Measurements*

Qualitative data were collected through written feedback for individual and small group stages. Participants were asked to complete written responses to a number of questions that had been developed for the study in their individual capacity (see appendix A). The large group consensus discussion also used written feedback, and the lead author collated information and themes generated during the workshop on a flipchart visible to participants and used to facilitate discussion and final consensus. In addition, the large group consensus discussion was audio-recorded and used to ensure accurate record keeping and summative analysis of discussions. No other measurements were used.

#### *4.2.5 Analysis*

The data from the workshop, including individually written responses, smaller group themes written by the scribes, written notes on the flipchart and audio recording of the larger group consensus discussion were collected. The Braun and Clarke (2006) 6-step framework was employed and the generated themes were used to do member checking to ensure a consensus interpretation of findings. The workshop process itself was a consensus building one and therefore independent coding by two coders as would be typical for standard qualitative analysis was not performed. Where data were not captured clearly, amendments were made and allowed the stakeholder panel to reach consensus through an iterative process. The data were summarised thematically by the authors as guided by the consensus-generated Evaluation Framework developed at the workshop. The themes that emerged from the multi-stakeholder process were mapped onto the implementation science literature after the data collection process.

### **4.3 Results**

#### *4.3.1 Participants*

Fourteen participants from a broad spectrum of professions and disciplines were recruited. These included 2 Child and Adolescent Psychiatrists; 1 Clinical Psychologist; 1 Educational Psychologist; 2 Speech and Language Therapists; 1 Occupational Therapist and a School Deputy Principal. Other participants included a Non-Governmental Organisation (NGO)

founder, an NGO counsellor, an NGO facilitator, 2 health systems researchers and an implementation science researcher.

In addition to their professions stakeholders represented 2 universities, 2 schools/ASD centres, 2 NGOs and 3 government departments (Health, Social Development, and Education). Two participants were parents/carers of individuals with ASD.

#### *4.3.2 The Evaluation Framework*

A graphic representation of the themes and components of the Evaluation Framework generated is shown in Figure 4.1. Three main themes emerged from the stakeholder workshop as guiding principles for the Evaluation Framework. These were 'Outcomes', 'Processes & Procedures' and 'Implementation Landscape'. We will outline main findings under the themes below. Under these themes a number of components with several criteria were identified. Components under 'Outcomes' included Parent, Child, Family and Community outcomes. Under 'Processes & Procedures' components included Accessibility, Acceptability, Psychological Processes and Referral Pathways. Under the theme of 'Implementation Landscape' components, were Sustainability, Integration & Coordination, Scalability and Monitoring & Evaluation. The full list of themes, components and criteria are detailed later in the ASD PET Evaluation Framework Checklist presented in Figure 4.2.



**Figure 4.1. Graphic representation of the themes and components of the Evaluation Framework**

*Theme 1: Outcomes*

Four key evaluation components were identified under theme 1. Parent-related outcome criteria included evidence of improvement in parental knowledge; beliefs and attitudes; emotional well-being (including stress reduction and increased hope); practical skills and an increased sense of empowerment, confidence and advocacy. Child-related outcome criteria included improvement in the child's quality of life; in the ASD-related deficits (e.g. social and communication) as well as in parent-specified outcomes in the child (e.g. specific behaviours or activities). Evaluation criteria identified in relation to family outcomes included improved quality of life of the family, reduced sense of family isolation, and access to and mobilising

support. Under the community component, stakeholders suggested as a criterion that evidence should be sought to determine whether the programme had a positive impact on the community, for instance, through reduced stigma or increased community knowledge about ASD.

### *Theme 2: Processes & Procedures*

A wide range of components emerged under the processes & procedures theme. Criteria under the accessibility component included whether the programme is accessible in terms of the language of delivery, location of the programme, cost (to both parent and programme provider) and literacy requirements of participants. The acceptability component of the programme included criteria relating to cultural considerations, trainers, age range, and materials (e.g. whether the programme is culturally acceptable to the parents/carers attending and whether the trainers of the programme are acceptable to the parents/carers). Under the psychological processes component, criteria included whether the programme structure was able to provide a psychologically 'holding' environment for parents/carers and whether it facilitated parent-to-parent support. An additional criterion examined whether there was evidence that the programme psychologically prepares parents/carers for next steps after the completion of the programme.

The final component under the processes & procedures theme was referral pathways and included two criteria: The first detailed if there was a clear referral protocol into the programme; the second asked whether there was a pathway for parents/carers to receive next-step interventions or support after completion of the programme.

### *Theme 3: Implementation Landscape*

Under this theme, criteria were divided under four components. The first component, sustainability, included four criteria. Criteria included buy-in of the programme provider, local and national government, rated as key to the uptake and sustainability of the programme. Further criteria included evaluation whether appropriate decision-makers and stakeholders are included in the implementation of the programme, whether there was evidence that the programme could be sustainable in the intended context, and whether there was evidence of the necessary funding.

The second component, integration & coordination included four criteria. The first explored whether there was integration and coordination of the programme between relevant systems and departments. The second criterion examined whether there was agreement about who would provide oversight and coordination of the programme. The third criterion ascertained if referrers, professionals and parents were aware of the programme.

The third component scalability contained two criteria. These explore whether training for the PET programme can be scaled-up (e.g. whether there is a train-the-trainer system), and whether there is there evidence that the programme can be replicated across different sites (e.g. whether the PET programme is manualised).

The final component, monitoring & evaluation explored whether there is a system to monitor and evaluate the programme over time, in order to ensure ongoing adherence to the outcomes, processes & procedures and other aspects of the PET programmes, in order to raise the need for programme adaptation as and when needed. The proposed Evaluation Framework checklist is included below in Figure 4.2.

# AUTISM SPECTRUM DISORDER PARENT/CARER EDUCATION & TRAINING EVALUATION FRAMEWORK CHECKLIST (ASD PET CHECKLIST)

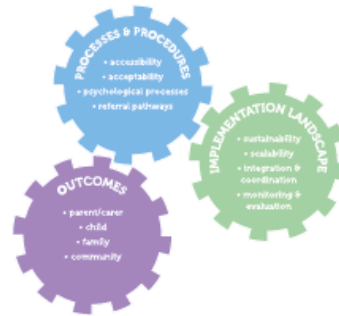
Name of Programme: .....

.....

.....

Completed by: .....

On date:   /   /



Outcomes		
PARENT/CARER OUTCOMES		Comments
1	Is there evidence that the programme leads to an increase in parent/carer knowledge?	Yes <input type="checkbox"/> No <input type="checkbox"/>
2	Is there evidence that the programme enhances beliefs and attitudes of parents/carers?	Yes <input type="checkbox"/> No <input type="checkbox"/>
3	Is there evidence that the programme supports emotional well-being of parents/carers including stress reduction, increasing hope, or managing grief, where applicable?	Yes <input type="checkbox"/> No <input type="checkbox"/>
4	Is there evidence that the programme increases parent/carer skills that are practical and can be applied in the context of home activities?	Yes <input type="checkbox"/> No <input type="checkbox"/>
5	Is there evidence that the programme leads to increased parent/carer empowerment, confidence, and positive advocacy?	Yes <input type="checkbox"/> No <input type="checkbox"/>
CHILD OUTCOMES		Comments
6	Is there evidence that the programme leads to an improvement in the child's quality of life and well-being?	Yes <input type="checkbox"/> No <input type="checkbox"/>
7	Is there evidence that the programme leads to changes in parent-specified outcomes (e.g. in specific behaviours)?	Yes <input type="checkbox"/> No <input type="checkbox"/>
8	Is there evidence that the programme leads to changes in ASD-related deficits (e.g. social and communication)?	Yes <input type="checkbox"/> No <input type="checkbox"/>

FAMILY OUTCOMES		Comments
9	Is there evidence that the programme leads to improvement in family quality of life (including siblings)?	Yes <input type="checkbox"/> No <input type="checkbox"/>
10	Is there evidence that the programme reduces family isolation?	Yes <input type="checkbox"/> No <input type="checkbox"/>
11	Is there evidence that the programme improves the family's access to, getting and mobilisation of support?	Yes <input type="checkbox"/> No <input type="checkbox"/>
COMMUNITY OUTCOMES		Comments
12	Is there evidence that the programme has a positive impact on the community (e.g. awareness, knowledge and stigma)?	Yes <input type="checkbox"/> No <input type="checkbox"/>

OVERALL EVALUATION OF OUTCOMES:

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## PROCESSES & PROCEDURES

ACCESSIBILITY		Comments
13	Is there evidence that the language of the programme is accessible to the target population?	Yes <input type="checkbox"/> No <input type="checkbox"/>
14	Is there evidence that the location of the programme is accessible to the target population?	Yes <input type="checkbox"/> No <input type="checkbox"/>
15	Is the cost of the programme for the providing organisation/department acceptable?	Yes <input type="checkbox"/> No <input type="checkbox"/>
16	If there is a cost to the parent/carer for attending the programme is it acceptable to the target population?	Yes <input type="checkbox"/> No <input type="checkbox"/>
17	Does the programme require literacy and is there evidence that this will impact accessibility?	Yes <input type="checkbox"/> No <input type="checkbox"/>
ACCEPTABILITY		Comments
18	Is there evidence that the programme is culturally acceptable to the target parents/carers?	Yes <input type="checkbox"/> No <input type="checkbox"/>
19	Is there evidence that the programme trainers are acceptable to the parents/carers?	Yes <input type="checkbox"/> No <input type="checkbox"/>

20	Is there evidence that the programmes materials are acceptable to parents/carers?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
21	Does the programme use a range of modalities to teach (e.g. home visits, experiential learning, video feedback, group discussion)?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
22	Is the age range of the programme suitable for the target population?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
23	Is there evidence that the timeframe of the programme is acceptable to parents/carers?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

PSYCHOLOGICAL PROCESSES	Comments
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24	Is there evidence that the programme informs and prepares parents/carers of next steps and support after completion of programme?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
25	Does the programme structure actively facilitate emotional containment or parent-to-parent support?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

REFERRAL PATHWAYS	Comments
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26	Is there a clear protocol for referral to the programme?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
27	Is there evidence that participants have access to next steps (e.g. step-up interventions as required) after the programme?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

OVERALL EVALUATION OF PROCESSES AND PROCEDURES:

## IMPLEMENTATION LANDSCAPE

SUSTAINABILITY	Comments
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28	Is there buy-in for the programme from providers, local and national government?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
29	Is there evidence that appropriate decision-makers and stakeholders have been included in the implementation of the programme?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
30	Is there evidence that the programme can be sustainable in the intended context?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
31	Is there funding for the programme (including proprietary costs)?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

INTEGRATION & COORDINATION		Comments
32	Is there integration and coordination of the programme between relevant systems and departments?	Yes <input type="checkbox"/> No <input type="checkbox"/>
33	Has there been agreement about who will coordinate, lead and provide oversight for the programme?	Yes <input type="checkbox"/> No <input type="checkbox"/>
34	Is there evidence that referrers, professionals and parents/carers are aware of the programme?	Yes <input type="checkbox"/> No <input type="checkbox"/>
SCALABILITY		Comments
35	Is there evidence that the training can be scaled-up (e.g. is there a train the trainer system)?	Yes <input type="checkbox"/> No <input type="checkbox"/>
36	Is there evidence that the programme can be replicated across different sites (e.g. is it manualised)?	Yes <input type="checkbox"/> No <input type="checkbox"/>
MONITORING & EVALUATION		Comments
37	Is there evidence of a system to monitor, support and adapt the programme as needed?	Yes <input type="checkbox"/> No <input type="checkbox"/>

OVERALL EVALUATION OF THE IMPLEMENTATION LANDSCAPE:

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OVERALL EVALUATION OF THE PROGRAMME:

Figure 4.2. ASD PET Evaluation Framework Checklist

After a final review of the draft Evaluation Framework, the multi-stakeholder group were asked for overarching comments about the consensus Evaluation Framework. These included firstly, that the framework emphasised that programme evaluation is about more than just efficacy (often used as the 'gold standard' in evidence-based medicine), and highlighted the importance of process and implementation as well; secondly, that the framework should be broad enough to be useful to researchers, policy makers, purchasers and providers; thirdly, that the framework could be useful at different stages of programme evaluation research e.g. as part of feasibility assessments, or for ongoing monitoring and evaluation. The panel, however, also raised the need to clarify or operationalise some of the identified variables (e.g. the role of trainers, stigma) and suggested that a shortened framework may be easier for implementation in real life.

#### **4.4 Discussion**

Given the multitude of ASD-specific PET programmes available, and the multiple and varied contexts in which they are provided, there is a clear need to establish a standardised set of criteria by which to evaluate such programmes. Given the current lack of a standardised tool, this study sought to develop a framework to evaluate ASD-specific PET programmes. Using an implementation science, multi-stakeholder participatory approach, an Evaluation Framework was generated.

One of the key findings of the multi-stakeholder Evaluation Framework was the importance of considering not only the primary outcome (e.g. parent-focused outcomes), but also to consider outcome in a broader context such as impact on child, family, siblings and the community. The focus of much of the outcomes-based research in ASD PET has been related to parents, for example, decreasing stress, or increasing knowledge (Farmer & Reupert, 2013; Tonge, 2006). The individual approach is broadly in line with evidence-based practice which emphasises "the conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient" (Sackett et al, 1996, p.71). The framework generated here highlights the importance that PET might have a broader reach than just the

individual parents/carers with possible positive outcomes that could be detected also in the individuals with ASD, their siblings and in the community.

The second key finding was the importance of considering processes & procedures in evaluating a PET programme. That is, even if outcomes are evaluated positively, there are cardinal process factors that need to be evaluated. For instance, acceptability and accessibility of a programme are potential barriers to the uptake of a programme. Implementation research literature considers identifying problems that hinder access to interventions and delivery of services as one of its core functions (Dunn et al., 2012; Proctor et al., 2011). The criteria listed under accessibility, for example, including language of delivery, literacy requirements, location and cost to both participant and provider are all potential barriers that may prevent parents/carers from attending despite the potential effectiveness of the programme. Cultural awareness and acceptability of a programme, particularly when developed in a different setting, is another important area to consider for implementation research (Cabassa & Baumann, 2013). For example, individuals are less likely to access treatments they consider unacceptable regardless of their effectiveness and are more likely to access treatments viewed by them as acceptable (Eckert & Hintze, 2000; Borrego & Pemberton, 2007). As pointed out by Cabassa & Baumann (2013), the use of cultural adaptation models in implementation research can make evidence-based programmes more responsive to the needs and preferences of diverse populations. The significance of ongoing monitoring of the acceptability and accessibility of programmes as they are developed and adapted, has also been highlighted in the literature (Proctor et al., 2011).

The third key theme of the Evaluation Framework generated here, referred to as the 'Implementation Landscape', indicates further areas critical to the broader expansion of the programme. Regardless of the positive evidence for good outcomes and processes and procedures, this final group of criteria of the Evaluation Framework will determine if it has the potential for scale-up and sustainability in particular. The key areas listed, including sustainability, integration & coordination, scalability and monitoring & evaluation of the programme are all considered critical areas of focus for implementation research (Damschorder, 2009; Milat et al., 2012). The necessity for programmes to consider scalability at early stages of implementation along with related factors of replicability and sustainability

has been described in the literature and this Evaluation Framework highlights their importance. The explicit consideration of funding, both at provider (e.g. for trainers, proprietary costs) and parent/carer level are related. In our scoping review of PET programmes, as outlined in chapter 2 and 3, we noted that implementation factors are often not considered in studies.

The implementation science emphasis on systems and the importance of stakeholder inclusion is further highlighted in the framework (Bammer, 2005). The identification of leaders and coordinators of a programme, whether there has been buy-in by providers, local and national government, whether funding decision makers have been included in the process, and whether a PET programme has been or can be integrated into existing systems and services, all highlight the complexity of scaling-up and scaling-out a PET programme. While the goal of many PET programmes may be to scale-up and remain sustainable (as is the case with many health promotion interventions), such a goal requires consideration of these components from the early stages of development and implementation of PET (Milat et al., 2012; Aarons et al., 2017).

Interventions are often referred to as ‘evidence-based’ when one or two very specific pre-specified outcomes have been positively improved by that intervention (Titler, 2007). Efficacy is therefore typically the primary goal of intervention research. Whilst necessary, it may not be sufficient for successful implementation in real-world settings. The Evaluation Framework generated here, emphasises the importance of additional factors that require consideration.

The Evaluation Framework therefore emphasises that programme evaluation for ASD PET requires balanced consideration of all three key themes in order to determine the most suitable programme for a particular setting at a particular time. As shown in figure 4.1 we used the image of three cogs to underline the fact that all three themes are required, and that problems in any of these may be associated with difficulties in real-life settings. The framework was developed out of a real-world problem in a low-resource environment. To our knowledge, this is the first multi-stakeholder generated evaluation framework developed for PET programmes in ASD. We hope that it may be useful not only in low-resource environments but in any setting where clinical, policy or purchasing decisions may need to be

made about ASD PET programmes. In specific settings the Evaluation Framework may also be used in conjunction with Theory of Change which is used frequently in the development and evaluation of complex interventions (de Silva et al., 2014). Such an approach might assist users of the framework with directly mapping essential components of an intervention and understanding their relatedness. Theory of Change maps describe how and why a programme works and could use data from the Evaluation Framework to ensure a comprehensive and detailed conceptualisation (Breuer et al., 2016). We anticipate that the Evaluation Framework might also have potential use for other ASD-specific interventions, for instance parent-mediated interventions, and potentially for other neurodevelopmental intervention programmes.

#### *4.4.1 Limitations*

We acknowledge some limitations in our study. This included the fact that we did not include individuals with ASD as stakeholders. However, given that the focus of our work was on parent education training, we felt that inclusion of parents/carers was key. We also acknowledge that the Evaluation Framework did not generate a specific scoring system. Whilst we initially set out to develop a scoring system, the feedback from the multi-stakeholder participants suggested that the different needs, contexts and purposes of programmes may be better suited to a non-quantified evaluation framework 'checklist'. That is, instead of proposing that a PET programme should score above a certain cut-off, evaluators can use the criteria as outlined to determine to what extent a potential programme may meet their specific needs. We also acknowledge that the framework was generated by stakeholders in a specific setting and that stakeholders around the globe may identify different or additional themes, components and criteria of relevance. With this limitation in mind, we included participants who had experience of working or doing research in a range of countries, which we hoped would increase the likely universal application of the Evaluation Framework. A final limitation is that there is currently no accompanying document to assist users of the framework. Such a document will need to be developed and may incorporate guidance and strategies used by other models such as PASSING (Programme Analysis of Service System's Implementation of Normalisation Goals) that use external evaluation teams (Wolfensberger & Thomas, 2007).

## **4.5 Conclusion**

ASD-specific PET programmes are considered an important component of support for parents directly after diagnosis. There is large variability in the PET programmes available and the contexts in which they are delivered. In the absence of any existing framework, we used an implementation science, participatory research strategy to generate an ASD evaluation framework to guide selection of programmes best suited to specific needs and environments. The framework emphasises the importance of both implementation and process factors in addition to outcomes when evaluating PET programmes for use.

## **4.6 Chapter summary**

The World Health Organization (WHO) resolution on Autism Spectrum Disorder (ASD) recommends access to intervention for parents and carers, including post-diagnostic psychoeducation, which is considered to be part of best practice. Globally, a broad range of Parent Education and Training (PET) programmes are available and are being delivered in a wide range of contexts and formats. Despite the clear need for PET, there is currently no generally accepted evaluation framework to determine which PET programme might be best suited to these different settings. This study aimed to generate such an evaluation framework using a multi-stakeholder approach.

Using an implementation science, multi-stakeholder participatory approach, purposive sampling was used to identify participants with expertise in clinical, educational or social aspects of ASD, in implementation and health systems, and parents/carers of individuals with ASD. A consensus building stakeholder workshop, using small and large groups, was facilitated by the lead author. Participants were asked to identify factors of relevance to implementation of an ASD-specific PET in a low-resource setting. Qualitative data collected from the workshops were analysed using a thematic analysis.

Fourteen participants from a range of disciplines and roles were recruited. Three main themes emerged from the workshop which guided the generation of the evaluation framework. These were 'Outcomes' (including parent, child, family and community outcomes), 'Processes & Procedures' (including accessibility, acceptability, a psychological process that actively facilitates emotional containment of participants, and referral pathways) and 'Implementation Landscape' (including sustainability, scalability, integration & coordination, and monitoring & evaluation). An Evaluation Framework Checklist was developed using these themes and was presented and discussed in the chapter.

This multi-stakeholder-generated evaluation framework emphasised the importance of a broad range of outcomes, of appropriate processes and procedures, and the importance of the implementation landscape as contextual factor for implementation of a PET programme for ASD. We propose that our Evaluation Framework could provide guidance to clinicians, researchers and policy-makers who may wish to evaluate ASD-specific PET programmes. We recommend exploration of the Evaluation Framework in a range of PET programmes presented at different intensities and frequencies, and across a range of geographical and differently resourced locations.

# Chapter 5

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## **A comparative feasibility study of two Parent Education & Training (PET) programmes in a low-resource South African setting**

### **5.1 Introduction**

Autism Spectrum Disorder (ASD) has clearly been recognised as a global public health concern, and the World Health Organization (WHO) resolution on ASD and related developmental disabilities (WHO, 2014) expressed deep concern about the fact that “children and families in need, particularly in low-resource contexts, often have poor access to appropriate supports and services” (WHO, 2014, p.2). The WHO resolution placed a strong emphasis on families and communities, and expressly recommended the need to provide social and psychological support and care to families affected by ASD. The resolution also highlighted the need for context-specific research on the public health and service delivery aspects of ASD (WHO, 2014).

The focus on families and communities as well as the need for education and support to families has been highlighted in the ASD literature (Bearss, et al., 2015; Gillespie-Lynch and Brezis, 2017) and reinforces the need for support and psychoeducation directly after diagnosis, as outlined in chapters 1, 2 and 3. In chapter 2 we outlined that various definitions have been used to describe the range of parent/carer-related interventions for ASD. The most well-defined taxonomy to date was articulated by Bearss and colleagues (2015) who differentiated between ‘parent support’ (to describe interventions where the parent was the direct beneficiary) and ‘parent-mediated intervention’ (to describe parent-led interventions where the child with ASD was the direct beneficiary). In a review of one specific ASD parent programme (Dawson-Squibb, Davids & de Vries, in press; chapter 2), we acknowledged that many parent support interventions may represent ‘hybrids’ between these broad groups as outlined by Bearss et al. (2015). For that reason, we selected to use a placeholder term –

Parent Education & Training (PET) – to describe the process of passing on information or skills to parents/carers using a range of modalities (e.g. didactic, role-play, discussions) in a context where parents/carers and trained facilitators are the direct participants. As noted, the focus of PET is on knowledge transfer to parents/carers and they are the main beneficiaries rather than emphasis being on the parent-child dyad (Dawson-Squibb, Davids & de Vries, in press).

A wide range of PET programmes are used across the globe, as reviewed in chapter 3. In the scoping review of one such widely-implemented PET programme, the EarlyBird/EarlyBird Plus (EB/EBP) programme developed in the UK, we were able to identify only relatively low-level of evidence for the outcomes of the programme, and found that relatively little research to date had been performed on implementation-related factors of the programme, such as expansion; practicality; accessibility and cultural appropriateness (Dawson-Squibb, Davids & de Vries, in press). This raised the question whether the findings were related only to these specific programmes, or whether it may have reflected the broader research field in PET. We therefore performed a broader scoping review to identify peer-reviewed publications on all PET programmes conducted outside the USA to date (chapter 3). Findings across all the PET programmes identified (37 publications on 34 unique PET programmes) were very similar to the EB/EBP results, with only a handful of randomised-controlled trials ever performed and limited implementation science investigation of these PET programmes (chapter 3). Another striking finding from both reviews was the fact that, to date, no consensus evaluation framework had been generated which may allow for a systematic examination of any PET programmes. Given the wide range of PET programmes in terms of location; duration; modalities and trainers, and the variability of outcome measures used, it therefore remained very difficult to make any direct comparison of PET programmes in order to evaluate or select a suitable PET programme for a specific context. We therefore used a multi-stakeholder strategy to generate an evaluation framework as a potential tool for the study of ASD PET programmes (see chapter 4).

Given the current state of PET research, particularly in low-resource environments where PET may be especially empowering to families, we set out to perform a head-to-head comparison of two PET programmes with low-resourced families in South Africa.

### *5.1.1 Two Parent Education & Training (PET) programmes under investigation*

We selected two PET programmes for examination and comparison in this study. EB/EBP was described in detail in chapter 2 (Dawson-Squibb, Davids & de Vries, in press). In short, EB/EBP were designed in 1997 and 2003 by the UK National Autistic Society. The primary aims of EB/EBP are 1) to support parents immediately after diagnosis; 2) to empower parents and encourage a positive perception of the child's ASD; and 3) to help parents establish good practice. To date, more than 27,000 families in 14 countries have attended the 12-week group-based programmes. The majority of research on EB/EBP reported positive outcomes, although the evidence-base comprised mostly lower-level strength and was exclusively from High-Income Countries (HIC). Chapter 2 and Dawson-Squibb, Davids & de Vries (in press) provide further detail about EB/EBP.

Autism Cares is a 5-day psychoeducation workshop for parents and professionals run through Autism Western Cape (AWC) in South Africa. AWC is a non-profit organisation that aims to provide information as well as advisory, advocacy and support services to those affected by ASD in the Western Cape. The Autism Cares programme was developed by an employee of AWC in an attempt to provide information about ASD and ASD services in Cape Town and the Western Cape in order to meet the needs of parents and professionals (Personal communication, Keri Delpport). The primary purpose of the workshop is to provide information to parents and professionals regarding ASD. The programme is run over five consecutive days, 6 hours per day. Each day covers a different module: 1) Understanding ASD; 2) Behaviour Management; 3) Early Learner Therapy; 4) ASD and inclusion in education; and concludes with 5) an ASD centre visit where parents and professionals can interact with children with ASD and observe relevant strategies being implemented.

Information and content for Autism Cares was gathered from a variety of sources and was adapted at the discretion of the course presenter, based on feedback from groups. No single theoretical model provides a foundation for Autism Cares, but a range of widely-used models and approaches are included (e.g. PECS, ABA, TEACCH) (Bondy & Frost, 1994; Foxx, 2008; Division TEACCH, 2002). The programme is aimed at both professionals and parents. A

maximum of twelve people may attend each group with one facilitator presenting the material. It is not aimed at any particular age-group of children with ASD. The teaching format includes a didactic approach, videos and some group discussion. Additional reading materials and worksheets are provided for participants. The programme is currently run only in Cape Town. To date, no formal research or evaluation has been performed on Autism Cares. The programme therefore has no existing evidence-base and no outcome measures have been included in the programme.

Table 5.1 below provides a summary of the two programmes while Table 5.2 outlines some of the obvious similarities and differences between these two programmes.

**Table 5.1. Description of EarlyBird/EarlyBird Plus and Autism Cares**

	<b>EarlyBird (EB) and EarlyBird Plus (EBP)</b>	<b>Autism Cares</b>
<b>Developed by</b>	National Autistic Society, UK	Autism Western Cape, South Africa
<b>Year of development</b>	1997 (EB), 2003 (EBP)	2014
<b>Aims</b>	1) to support parents immediately after diagnosis 2) to empower parents and encourage a positive perception of their child's ASD 3) to help parents establish good practice	to provide parents and professionals with information regarding ASD
<b>Target population</b>	Parents of children recently diagnosed with ASD EB – preschool children EBP – school-going children up to 8y 11m	Parents and professionals wanting to learn more about ASD

<b>Course length</b>	2.5 hours per week for 12 weeks  Total = 30 hours	6 hours per day for 5 consecutive days  Total = 30 hours
<b>Facilitators and training</b>	2 trained and licenced facilitators per programme	1 facilitator per programme, no current programme to train facilitators
<b>Participants per group</b>	EB – 6 families (2 individuals per family)  EBP – 5 families plus one professional per family (selected by the parents, e.g. classroom assistant)	up to 12 participants can attend per group (mixture of parents and professionals)
<b>Number of countries delivering programme</b>	14	1
<b>How many have attended</b>	27000+ families	Not documented

**Table 5.2. Comparison of EarlyBird/EarlyBird Plus and Autism Cares**

	<b>EarlyBird and EarlyBird Plus</b>	<b>Autism Cares</b>
<b>Similarities</b>		
<b>Overall focus</b>	Overall focus on support, education and upskilling of parents through group work	Overall focus on education and upskilling of parents and professionals through group work
	Focus on ASD	Focus on ASD
	Focus on behaviour, communication and socialisation	Focus on behaviour, communication and socialisation

<b>Differences</b>		
<b>Length</b>	Weekly group sessions with 3-month time commitment	5 consecutive days, six hours per day
<b>PET components</b>	In addition to psychoeducation, focus on support and upskilling of parents as well as stress reduction	Main aim to impart information to parents and professionals
<b>Modalities of delivery</b>	Didactic presentation and teaching; group activities; large and small group discussion; video vignettes; parent book; homework tasks; home visits	Didactic presentation; group work; video vignettes and handouts/reading material; visit to an ASD centre
<b>Research evidence base</b>	Lower strength evidence from HIC indicating strong acceptability and efficacy	No previous or formal research on the programme's efficacy
<b>Training</b>	Costly facilitator training only available in the UK through NAS	No model or structure for facilitator training
<b>Manualisation</b>	Well-established protocol and course content, including facilitator manual and parent handbook	Adaptable protocol, not currently manualised
<b>Awareness of culture diversity in programmes</b>	Programme originally designed for a UK population with little overt emphasis on cultural appropriateness for other countries	Programme specifically designed for local population in Cape Town, South Africa
<b>Monitoring and fidelity</b>	Programme run internationally with regular feedback and central monitoring of facilitators through well-established parent questionnaires ensuring quality and fidelity	No established system for fidelity of facilitators. Limited parent feedback monitored by course facilitator
<b>Proprietary concerns</b>	The clearly structured and manualised programme material and training is provided by the National Autistic Society based in the UK. They have copyright of the material. Any adaptations or changes to the programme are done only with their permission.	Programme and material designed for local population is non-proprietary and adapted as required

We set out to do a comparative feasibility study with two main goals. Firstly, using the feasibility framework of Bowen et al. (2009), we opted to use a mixed-methods examination of the two programmes with emphasis on acceptability, adaptation, and limited efficacy-testing. A summary of the definitions is outlined in Table 1.1 (see chapter 1, p.20). Our second goal was to use the newly-generated multi-stakeholder evaluation framework (see chapter 4) to perform a head-to-head comparison of the two programmes. The purpose of this step was, in part, to summarise the mixed-methods feasibility results, but also to investigate the utility of the PET Evaluation Framework.

We predicted that the programmes would show some degree of parental acceptability and, based on previous EB/EBP research, some positive outcomes. It was predicted that there would be some adaptations required regarding the programmes in this Low-and-Middle-Income-Country and culturally diverse setting, particularly in relation to language and local services. Comparatively, we predicted that EB/EBP would be better able to support parents than Autism Cares though would be relatively less strong regarding local content.

## **5.2 Methods**

### *5.2.1 Study design*

This study incorporated a mixed-methods design, gathering both qualitative and quantitative data. To examine feasibility, we specifically investigated acceptability, adaptation and limited efficacy-testing as defined in Table 1.1 (see chapter 1, p.20). We opted for a quasi-experimental pre-post design with data collection at baseline, throughout the programmes, on conclusion, and three months after conclusion. After analysis of PET findings, a multi-stakeholder panel was convened to generate a consensus head-to-head comparison of the two programmes using the multi-stakeholder Evaluation Framework generated (see chapter 4).

## *5.2.2 Participants*

### *5.2.2.1 Parents/carers*

Convenience sampling was employed and the standard EB/EBP procedures were used for recruitment of EB/EBP and Autism Cares participants using a consolidated ASD waiting list held by the Department of Education in the Western Cape. Participants were assigned to programmes sequentially rather than randomly. Inclusion criteria for parents in the study were 1) having a child with an existing clinical diagnosis of ASD; 2) parents had to be interested, willing and able to attend the programmes; 3) parents/carers had to have a sufficient mastery of English to participate; and 4) provided written, informed consent.

### *5.2.2.2 Multi-stakeholder Panel*

All multi-stakeholders involved in the generation of the evaluation framework (chapter 4) were invited to participate in the programme evaluation phase. We aimed to have a review panel with >5 members.

## *5.2.3 Research procedures and data collection*

After completing standard training in the UK, the two facilitators for EB/EBP (the author and a colleague from Autism Western Cape) were licenced as EB/EBP facilitators. They therefore ran the EB/EBP programme. The same colleague from Autism Western Cape developed the AC programme and acted as facilitator.

Following recruitment and consent, participants completed pre-programme questionnaires and individual interviews. The EB programme was run from April to July 2016 and EBP from July to October 2016. Two Autism Cares courses were run in September and October 2016. Participants completed post-programme questionnaires and individual interviews within three weeks of programme participation. The EB/EBP post-interviews were completed by an independent interviewer who was not a facilitator of either of the programmes. The Autism Cares post-interviews were completed by the author (JJDS) who was not a facilitator of the Autism Cares programmes. Three-month follow-up questionnaires and interviews with participants were completed by the author.

Following completion of the programmes the author presented both the quantitative and qualitative data to the multi-stakeholder panel over two half-day meetings (see Table 5.7).

#### *5.2.4 Measures*

A combination of standardised and customised measures were used. Where researchers were required to choose between measures (e.g. there are multiple instruments measuring parental stress) preference was given to those that 1) had been previously used in PET studies; 2) could be meaningfully completed by participants in LMIC and 3) were available to researchers. The measures chosen were:

*5.2.4.1 Demographic Questionnaire.* This questionnaire captured standard demographic information including age, gender, marital status, household income and location. A social support question, drawn from Myer, Stein, Grimsrud, Seedat & Williams (2008), was also included in the questionnaire. See Appendix B for the demographic questionnaire.

*5.2.4.2 The Parenting Stress Index – Short Form (Abidin, 1995).* This widely-used questionnaire was developed to identify stressed or dysfunctional parent-child systems and facilitate intervention before the development of behavioural and emotional problems. It has a primary focus on preschool children and has been normed on over 2500 children. The short form is made up of 36 items with three subscales: Parental Distress (PD), Parent-Child Dysfunction (PCDI) and Difficult Child (DC). The three subscales consist of 12 items and the combined score of the three subscales contribute to a Total Stress Score which is determined as a percentile. A high score on each scale indicates a high level of stress. The short form uses a 5-point Likert Scale. This measure is widely used across a range of research and clinical spheres, including previous research on the EB/EBP programmes making it a suitable instrument for this research.

*5.2.4.3 Semi-structured Interview Questions (SSI).* The pre- and post- semi-structured interview questions covered a broad range of areas to give participants the opportunity to comment both on their experience and on the feasibility of the programme they attended. The pre-programme interview explored parents' current concerns, expectations for the course, and access to support. The post-interview asked parents about their experiences, perceived outcomes and acceptability, to suggest changes or additions they would make to

the programme, and how it has changed their day-to-day interactions with their child. The questions were used as a guide during the interview to elicit themes from parents. All participants (EB/EBP and Autism Cares) had pre- and post SSI. See Appendix C for the SSI questions.

*5.2.4.4 Parent Programme Satisfaction Measure.* This questionnaire was custom-designed for the purposes of this feasibility study and covered areas pertinent to the specific parenting programmes examined. The questions included a combination of 7-point Likert scale measures and qualitative questions and covered four broad topics, including the overall group, the teaching format, the facilitators and group participants.

*5.2.4.5 Parent Involvement Questionnaire – Knowledge of ASD section (Solish & Perry, 2008).* This questionnaire was designed to explore parent involvement in Intensive Behaviour Intervention for ASD (IBI) (Solish & Perry, 2008). The parent self-report questionnaire included 96 questions covering five independent variables including parental self-efficacy, knowledge of ASD, belief about IBI, perception of child progress and stress. For the purposes of our study, only the knowledge section was used to evaluate changes in parental knowledge of ASD. This section consisted of 10 questions where parents marked True, False or Don't Know to statements about ASD. The questionnaire evaluates different types of ASD knowledge specifically focusing on prevalence and symptoms (see Appendix D for examples of questions). A higher score suggested a better knowledge of ASD. Previous research on this questionnaire has indicated significant correlation between parental involvement and scores on the knowledge, belief and self-efficacy sections suggesting it could measure relevant change in a reliable way (Solish & Perry, 2008). The questionnaires simple format further made it an appropriate choice for the study population.

*5.2.4.6 Autism Treatment Evaluation Checklist (ATEC) (Rimland and Edelson, 1999).* This questionnaire was developed to measure changes in response to treatment. The ATEC is a 77-item questionnaire that can be completed by parents, teachers and carers. It includes four subtests: 1) Speech/Language communication (14 items); 2) Sociability (20 items); 3) Sensory/cognitive awareness (18 items) and 4) Health/Physical/Behaviour (25 items). Total scores range from 0-180 with a higher score generally indicating a greater degree of impairment. The ATEC has been reported to be reliable, valid and significantly correlated to

the Childhood Autism Rating Scale and has been used in a range of studies to assess change (Schopler et al., 1980; Geier, Kern & Geier, 2013).

5.2.4.7 *ASD PET Evaluation Framework Checklist* (Dawson-Squibb & de Vries, chapter 4). The Evaluation Framework was generated as part of this study using a multi-stakeholder implementation science approach (see chapter 4 for details). The ASD PET Evaluation Framework Checklist includes three main themes ('Outcomes', 'Processes & Procedures' and 'Implementation Landscape'), each with a number of components and criteria.

### 5.2.5. Data Analysis

Data were analysed under the three main headings of interest – acceptability, adaptation, and limited efficacy-testing. Table 5.3 shows a summary of data used under each heading.

**Table 5.3. Data used for evaluation of feasibility domains of interest**

<b>Feasibility domain</b>	<b>Measures</b>
<b>Acceptability</b>	Parent programme satisfaction measure
	Semi-structured interview questions
<b>Adaptation</b>	Parent programme satisfaction measure
	Semi-structured questionnaire
<b>Limited-efficacy testing</b>	Parenting Stress Index
	Parent involvement questionnaire (knowledge of ASD section)
	Autism Treatment Evaluation Checklist
	Semi-structured interview questions

All quantitative data gathered from the pre- and post-questionnaires were scored as pre-specified by individual measures and entered for descriptive pre-post analysis. Measures designed for this study were entered for descriptive analysis. Given the small sample size in EB and EBP, data were combined for the two programmes. Given that this was a comparative feasibility study, we did not include any inferential statistics.

Qualitative data from the pre- and post- semi-structured interviews were audio recorded for verbatim transcription and thematic analysis, using the 6-step process outlined by Braun & Clarke (2006). These 6 phases were: 1) familiarising with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6)

producing the report. Nvivo software was used to facilitate this thematic analysis (Nvivo, 2016).

The multi-stakeholder panel was given access to all data, and discussions continued on each theme and component until consensus was reached. Where consensus could not be reached due to a lack of data, this was indicated.

#### *5.2.6 Ethics*

Ethics approval for the study was granted by the Human Research Ethics Committee in the Faculty of Health Sciences, University of Cape Town (HREC ref: 007/2016) (see Appendix D for HREC approval form). The study was classified as minimum risk. All participants (families and multi-stakeholder participants) provided written, informed consent (see Appendix E for study information sheet and consent form).

### **5.3 Results**

#### *5.3.1 Participant Demographics*

Eleven families participated in the EB/EBP programme (5 for EB and 6 for EBP), consisting of 23 individuals in total. For research purposes only main carers were asked to complete the questionnaires, which resulted in a total of 18 completed datasets (EB=11; EBP=7). For the AC programmes, 10 families were included, and of those 11 parents attended the programme and completed the questionnaires. The ages of children with ASD in the families ranged from 3years 1months to 7years 4months for EB/EBP, and 3years 1month to 8years 11months for Autism Cares.

The socio-demographic characteristics of families were broadly similar in terms of male/female ratio; age; language; **self-assigned race**, household income and child's age. These are detailed in Table 5.4.

**Table 5.4. Demographics of participants**

	<b>EarlyBird/EarlyBird Plus</b>	<b>Autism Cares</b>
<b>Number of participants</b>	18	11
<b>Families</b>	11	10
<b>Male/Female</b>	28% male 72% female	9% male 91% female
<b>Age</b>	18 – 29years; 28% 30+ years; 72%	18 – 29years; 27% 30+ years; 73%
<b>Language</b>	English; 67% Xhosa; 11% Afrikaans; 6% Bilingual; 6% Other; 11%	English; 45% Xhosa; 27% Afrikaans; 9% Bilingual; 18%
<b>Self-assigned Race</b>	Coloured; 61% Black; 22% White; 17%	Coloured; 55% Black; 27% White; 18%
<b>Monthly Household income</b>	ZAR 0 – 5000; 39% ZAR 5000 – 25000; 56% ZAR 25000 – 100000; 6%	ZAR 0 – 5000; 36% ZAR 5000 – 25000; 56% ZAR 25000 – 100000; 9%
<b>Age of child with ASD</b>	3 years 1 month – 7 years 4 months	3 years 1 month – 8 years 11 months

\*ZAR 5000 ~ US\$ 400/GBP 300

### 5.3.2 Feasibility findings

#### 5.3.2.1 Acceptability

##### **Post-programme parent satisfaction measure**

In this section we present results for both PET programmes on a) modalities and components of the programme, b) whether participants would recommend it to others, and c) overall satisfaction with the programme, group and facilitators.

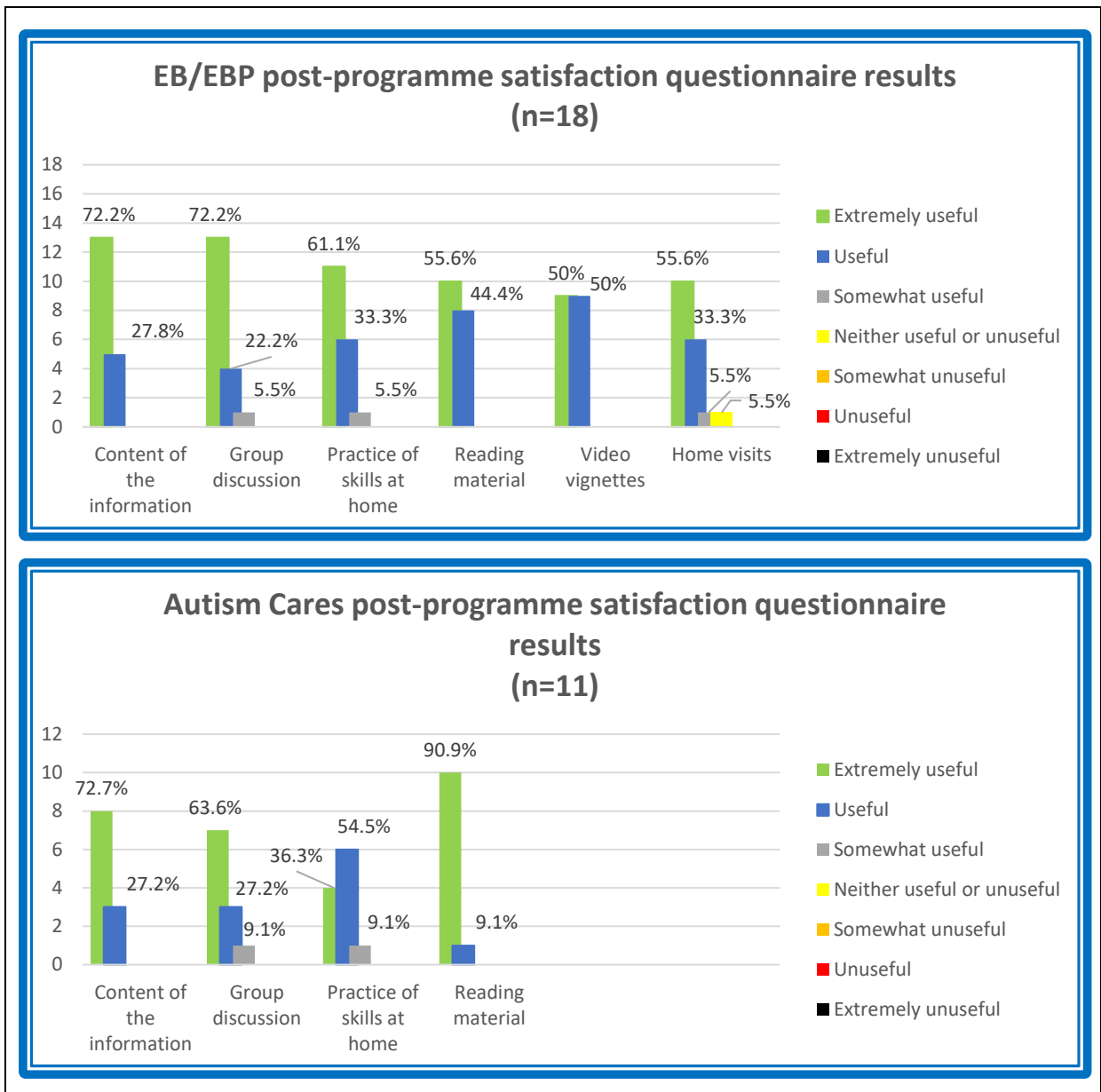
For EB/EBP all respondents (18/18, 100%) rated the content, video vignettes and reading materials as ‘useful’ or ‘extremely useful’. The majority of participants (15/18, 83.3%) rated group discussions, home practice and home visits also as ‘useful’ or ‘extremely useful’, with a handful of reports (3/18, 16.6%) indicating that it was ‘somewhat helpful’ or ‘neither helpful’.

nor unhelpful'. No negative EB/EBP responses were given. Results are summarised in Figure 5.1.

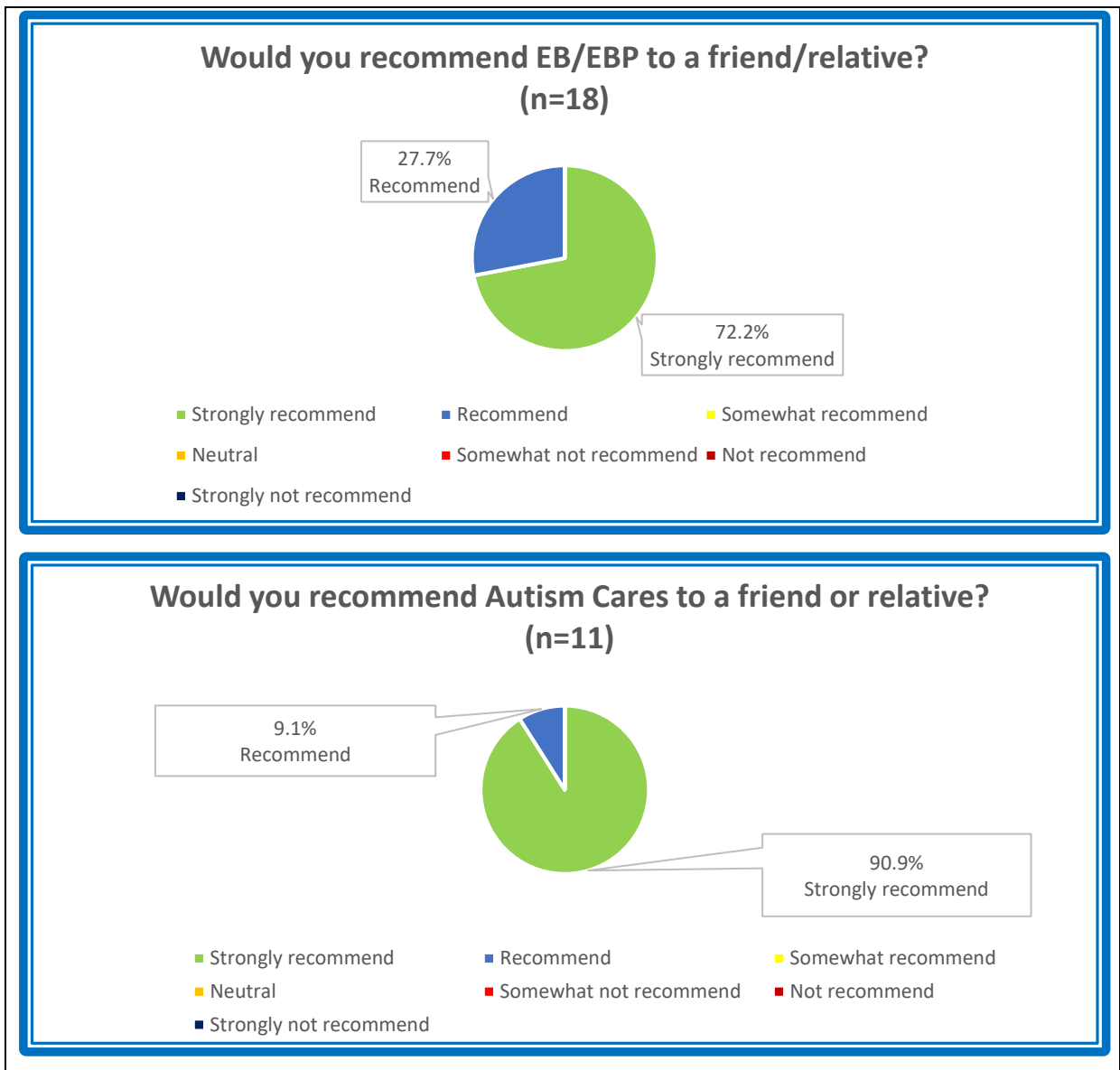
For Autism Cares the majority (9/11, 81.8%) of respondents rated group discussions, practice at home and reading materials as 'useful' or 'extremely useful'. A small number (2/11, 18.1%) found the group discussion and home practice 'somewhat useful'. No Autism Cares responses were negative. Results are shown in Figure 5.1.

As shown in Figure 5.2, thirteen of eighteen participants (72.2%) would 'strongly recommend' EB/EBP to a friend/relative and 5/18 (27.8%) would 'recommend' it. None would 'only somewhat recommend' it or 'not recommend' it. Ten of the eleven (90.9%) Autism Cares participants would 'strongly recommend' it to a friend/relative and one (9.1%) would 'recommend' it. None would 'only somewhat recommend' it or 'not recommend' it (see Figure 5.2).

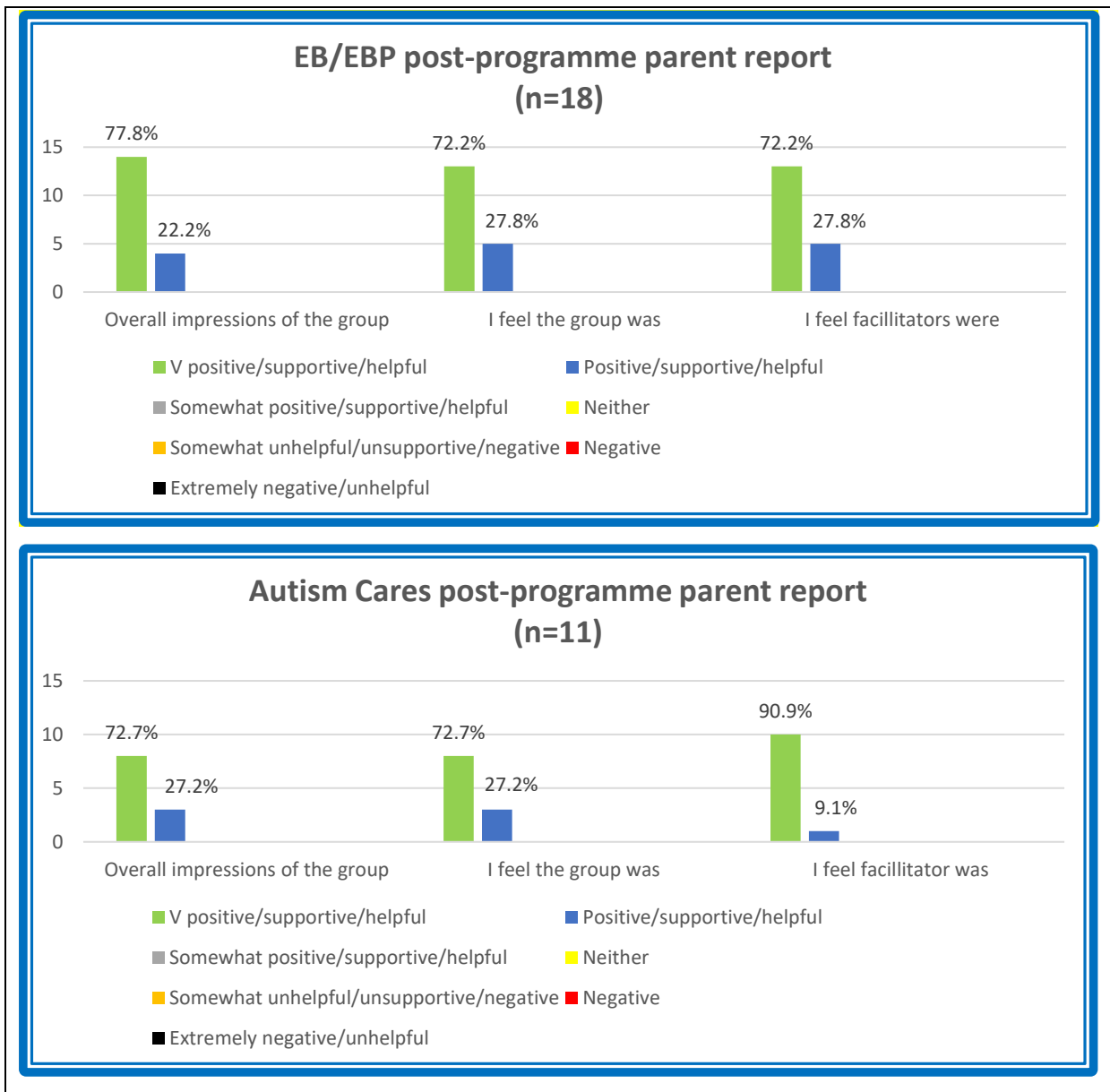
Fourteen of the 18 participants (77.8%) reported their overall impression of the EB/EBP group as being 'very positive', and four (22.2%) were 'positive'. Thirteen felt the group (72.2%) was 'very supportive' and five (27.8%) found it 'supportive'. Thirteen (72.2%) found the facilitators 'very helpful' and five (27.8%) found them 'helpful' (see Figure 5.8). Eight (72.7%) of the participants reported their overall impression of the Autism Cares group as being 'very positive' and three (27.2%) were 'positive'. Eight (72.7%) felt the group was 'very supportive' and three (27.2%) found it 'supportive'. Ten (90.9 %)found the facilitator 'very helpful' and one (9.1%) reported the facilitator as being 'helpful'. The above results are displayed in Figure 5.3.



**Figure 5.1. EarlyBird/EarlyBird Plus and Autism Cares post-programme satisfaction questionnaire results**



**Figure 5.2. EarlyBird/EarlyBird Plus and Autism Cares – would you recommend the programmes to a friend/relative?**



**Figure 5.3. EarlyBird/EarlyBird Plus and Autism Cares post-programme reports**

**Semi-structured interview themes**

Five themes from the semi-structured interviews related to acceptability of EB/EBP and Autism Cares. An additional two acceptability themes were relevant only to Autism Cares (attendance of professionals alongside parents, visit to an ASD centre).

## Theme 1: PET as helpful, relevant and appropriate

### **EarlyBird/EarlyBird Plus**

In 10 of the 11 interviews parents specifically noted that the programme had met their needs. Four of the 10 spontaneously remarked that it had exceeded their expectations or needs. All of the parents noted, often in effusive language, that they found the EB/EBP helpful, relevant and appropriate. The quote below from one of the interviews reflects an example of the impact the participants felt the programme had on them:

*“Everything that we know about autism is thanks to the EarlyBird Programme. Remember, we went in this blind.... but now we can see.”* [PRN13]

None of the interviewees commented that the programme was not helpful or relevant.

### **Autism Cares**

Eight of the 10 interviewees commented that the programme met their needs and expectations. Three of those spontaneously reported that it exceeded their expectations. Participants in all ten of the interviews indicated that they found the programme helpful, relevant and appropriate. A representative quote from one parent illustrates the point:

*“Yes, definitely it was. It was appropriate because it could give information that ...we were wondering about, ...like why is he doing certain things at certain times, so it was very informative, it was appropriate.”* [PRN27]

Five respondents commented that some of the information in the programme was not always relevant. One parent reported that some of the information was relevant to professionals rather than parents. Another parent reported that the information relating to Individual Education Plans was not applicable to her child (who was not yet attending school). The mother and father of another child reported that the information on toilet training was not relevant to their needs, and one parent reported that some of the information regarding toilet training could not be used because of her home environment where the toilet was outside.

## Theme 2: PET in a South African context

### **EarlyBird/EarlyBird Plus**

In six of the 11 interviews it was reflected that this kind of programme is needed in South Africa (*"We need it badly, so badly"*, PRN15). In five of the interviews it was specifically reported that the programme was culturally acceptable in a South African context. None of the parents reported that any parts of the course were not acceptable. A parent (comment below) reported on her thoughts regarding the programme in a South African context:

*"I don't know where else would you go for something like this... we've taken him since he was diagnosed...all around the Western Cape, to so many people and places. But it's a bit here and a bit there. ...with EarlyBird, you're getting this whole package, where they're pulling things together, explaining why. With support groups, every month they would have a different topic, but it's like the big elephant, you know, now it's the head and now it's the foot and now it's the tail. But with this EarlyBird Program, it's a sort of a package"* [PRN11].

### **Autism Cares**

In nine of the 10 interviews parents commented that the programme was needed in South Africa. The topic of cultural diversity was raised in four of the interviews. Reflecting on the different cultural backgrounds of participants in the group, one commented:

*"I found it quite fine. I think we all got along and I think autism kind of brings us together because we are all in the same situation... and I think we just want the best for our children. And we said being in South Africa there's not much support that you can get"* [PRN25].

## Theme 3: Acceptability of the content, parent book, transport, time/length and facilitators

### **EarlyBird/EarlyBird Plus**

All parents commented that the content, parent book and facilitators were acceptable. The parent book was rated highly by many of the parents as reflected in this exchange when a mother and father were asked what they thought of the book:

*"Perfect."*

*"Ah, this is like, not leaving the house at all."*

*"Ja...that's our autism bible."* [PRN1 & PRN02].

Parents also reflected positively on the facilitators, indicating that they were acceptable in

many different ways and contributed to the course.

The time and length of the programme was commented on in 9 of the 11 interviews. Three of those commented that they would have preferred longer sessions, specifically to allow for more group discussion time. The others reported that the time allocated was sufficient and that longer sessions would have made it difficult to concentrate. Seven of the 11 interviewees commented that having the course on a Saturday was most helpful.

Only one interview reflected concerns regarding transport and that this may make it difficult for others (though not the interviewee themselves) to attend the course. No other interviewees raised concerns regarding transport and five specifically commented that it was not an obstacle.

### **Autism Cares**

Six interviews reflected on the programme content. While also commenting positively on it, three indicated they would have preferred additions or changes. These and further additions and changes will be discussed in more detail in the adaptations section. Regarding the written material given to parents, five interviewees reported that they found them helpful and easily accessible, but three reported having some difficulty with the written material. All three commented that they were able to access a dictionary or ask the facilitator when they were unable to understand.

Regarding transport, two parents commented that transport might be difficult for others. Four reported no difficulties with accessing transport to the venue. The length of the course came up in eight of the interviews. Two parents reported that the time of the course from 9am – 4pm was too long, while three reported that the duration of sessions was acceptable to them. Six interviewees suggested that the course should be spread out over a longer period of time rather than on five consecutive days, and three of those reported they would have preferred there to be more space between the sessions to allow them to implement some of the information and skills they had learned. Parents were very positive about the facilitator. The facilitator's experience, knowledge and practical expertise, in particular, were commented on as important areas that made her trustworthy and acceptable. No parents reported any concerns about the facilitator.

## Theme 4: Language

### **EarlyBird/EarlyBird Plus**

Six of the interviews raised language as a theme. Six of the parents commented that while their first language was not English, they preferred the course to be taught in English. As explained by two parents, translating from English to other languages (in this case Afrikaans) could result in formal language that would be hard to understand. The suggestion was that the facilitators should be able to explain any complex English words as necessary. Two of the interviewees suggested that there should be an interpreter during sessions.

Four interviewees commented that the videos had heavily accented speakers which made them difficult to understand. It was noted by all of those who commented on this that the facilitators were able to explain to the group what was being said. An example given by a parent confirmed UK versus South African English not to be an insurmountable barrier to understanding:

*“Ja, it’s fine, it was like, just sometimes they will go like, for a soda or a packet of crisps, but we all know that is like a cooldrink and a packet of chips.” [PRN20].*

### **Autism Cares**

Four parents commented that the language of the course was problematic for their understanding. Three of them reflected that translation of the course materials would be helpful. As noted in the quote below some parents did not think that the course should be translated as this might hinder their understanding.

*“I think that I would probably not understand that Afrikaans, even though my home language is Afrikaans. But I think I enjoyed it in the English. We don’t speak that high Afrikaans, I would say...for me, Afrikaans is a bit more difficult to understand, than what English is.” [PRN27]*

*“Okay, so you’re worried that if it was translated to Afrikaans, it wouldn’t..’ [Interviewer]  
“I’d get lost.” [PRN27].*

## Theme 5: Support from the group

### **EarlyBird/EarlyBird Plus**

A particularly strong theme from the interviews regarding acceptability, was the role the group played in supporting parents. Nine of the interviews specifically commented on this raising it as a highly valuable part of the programme. The quote below reflects the impact that meeting others in similar positions can have in sharing information and reducing isolation:

*“For me it was just the understanding that there’s other people also going through that same thing and they could share with one another and that was an eye opener for us, especially for me. Look we were never exposed before to autism... for us it was a first time.. it stood out for me. Just the sharing with one another. Each one’s going through different things and how we can learn from one another.” [PRN09].*

The interviews also revealed that parents in EB/EBP programmes started a WhatsApp group which they continued to use as a form of support.

### **Autism Cares**

Eight of the interviewees commented on the benefit of meeting other parents in similar situations and gaining advice or support from them. One interviewee (the only male in the group) commented that he would have liked to have other fathers attend and that being the only male, he felt a little intimidated in sharing with the group. Three of the participants commented on joining a WhatsApp group with those in the group who lived close to them.

## Theme 6: Parents vs Professionals attendance of Autism Cares

There were mixed comments on professionals attending the programme. Seven of the interviewees indicated that they preferred having professionals there. They cited being able to get different perspectives from a range of professionals, sharing their views with professionals, gaining confidence in speaking to professionals and the importance of broadening awareness as reasons for including them. One parent did not have particular views either way, while two parents reported that they would have preferred separate courses for parents and professionals.

## Theme 7: ASD Centre Visit in Autism Cares

In the Autism Cares PET families are provided with an opportunity to visit an Autism Centre and interact with another child who has ASD. This was reflected on in six interviews. Four of those commented on the benefit of that experience, and 5 reported that the experience had been an emotional one (anxious, heartbreak, tearful), although all felt that those emotions had been contained and the experience had been an acceptable one.

### *5.3.2.2 Adaptation*

#### **Parent Satisfaction Questionnaire**

##### **EarlyBird/EarlyBird Plus**

In the parent satisfaction questionnaire, participants were asked to respond to the statement 'how could the programme have been improved to help you more?' The most common response (by 9/18 of the respondents) was that no adaptations were required. Where adaptation suggestions were made, a request for more sessions and more time in the sessions was an emerging theme (5/18). Other suggestions for changes included the need to make the video clips more understandable and there was a suggestion for a similar programme for children with ASD to help them 'handle' their ASD.

##### **Autism Cares**

Four of the respondents suggested that no changes were required, while two reported that they would have liked to have more time, i.e. more days in the programme.

A number of other one-off recommendations were made. These included having a separate session for parents and specialists, having a downloadable 'blueprint' of the course on a website, and having adults with ASD come in to speak to parents.

#### **Semi-structured interviews**

##### **EarlyBird/EarlyBird Plus**

A number of adaptations were suggested by participants during the semi-structured interviews. In total, 46 comments regarding adaptations were made during the 11 interviews. These adaptations have been summarised in Table 5.5 below with the number of interviews in which they were reported.

**Table 5.5: EB/EBP adaptations recommended in semi-structured interviews**

<b>Adaptation</b>	<b>Reported by (n=)</b>
Update videos	8
Change video language	3
More group discussions	3
More time in sessions	3
Adapt parent book	3
On-going support/refresher course	3
External speakers (e.g. Occupational Therapist)	2
Provide list of ASD services/schools	1
Provide transport for parents	1

### **Autism Cares**

A number of adaptations were suggested by participants during the semi-structured interviews. A total of 54 comments regarding adaptations were made during the 10 interviews. These adaptations are reported in Table 5.6 with the number of interviews in which they were mentioned.

**Table 5.6: Autism Cares adaptations recommended in semi-structured interviews**

<b>Adaptation</b>	<b>Reported by (n=)</b>
Home visit	7
Run programme on weekends	3
Interpreter present during sessions	3
More practical strategies	2
More group discussions	2
Aim at older children	2
Include South African videos	1

Less emotionally evocative videos	1
Venue closer to home	1
More information on communication and behaviour	1
Practice with children	1
Course material to be available online	1
Specialists to give input/talks	1
Provide links to trustworthy websites	1
Suggestions for next steps after programme	1
Follow-up course	1

### 5.3.2.3 Limited efficacy-testing

#### Quantitative results

Efficacy-testing focused on parental knowledge about ASD, parental stress and parental report of child changes, as measured by validated measures, and on parental perception of change in themselves and their children, as measured by the qualitative interviews.

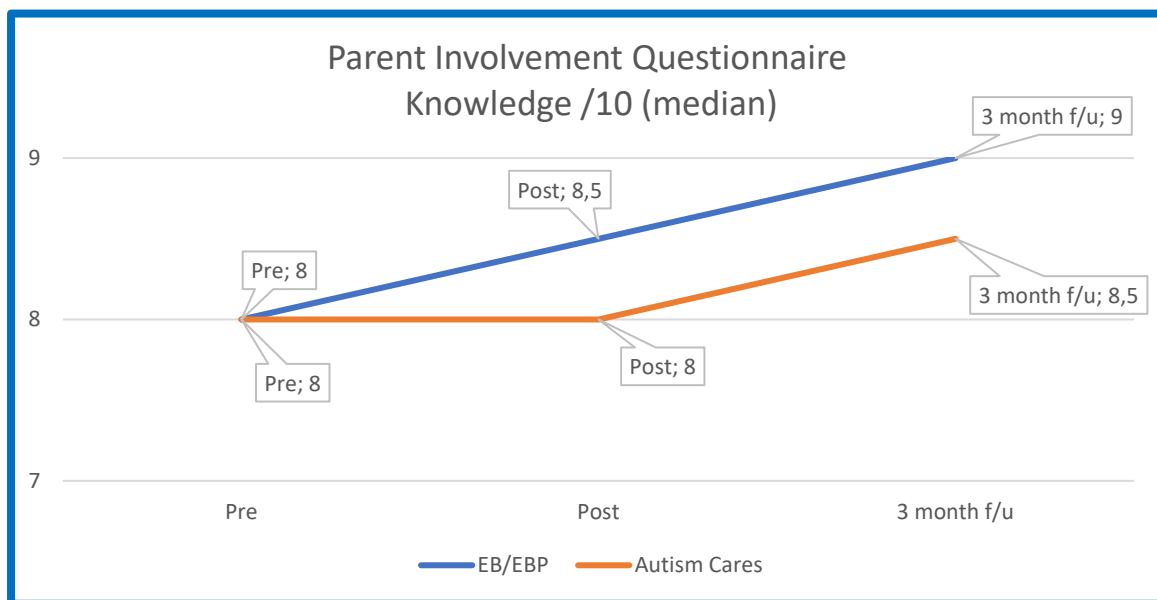
On the PIQ knowledge items (Solish & Perry, 2008), parental knowledge in both groups started at a high baseline (EB/EBP = 8/10, Standard Deviation (SD) = 1.81; Autism Cares = 8/10; SD = 2.87), increased somewhat on completion of the PET programmes (EB/EBP = 8.5/10, SD = 1.94; Autism Cares = 8/10, SD = 2.41) and increased to 3-month post-evaluation (EB/EBP = 9/10; SD = 2.1; Autism Cares = 8.5/10, SD = 1.77) (see Figure 5.4).

On the PSI (Abidin, 1995) the total parental stress index remained relatively unchanged in the Autism Cares group from pre- to 3-month follow-up, but showed a mean reduction of 14 percentile points in the EB/EBP group in the same time frame (Figure 5.5). The median pre-programme percentile scores were EB/EBP = 68 (SD = 16.36) and Autism Cares = 74 (SD = 20.67). The median post-programme scores were EB/EBP = 64 (SD = 25.76) and Autism Cares = 76 (SD = 8.25). The 3-month follow-up median scores were EB/EBP = 54 (SD = 14.62) and Autism Cares = 75 (SD = 12.29). Defensive scoring was noted in four of the participants for EB/EBP (1 post-programme and 3 at 3-month follow up) and one for Autism Cares (post

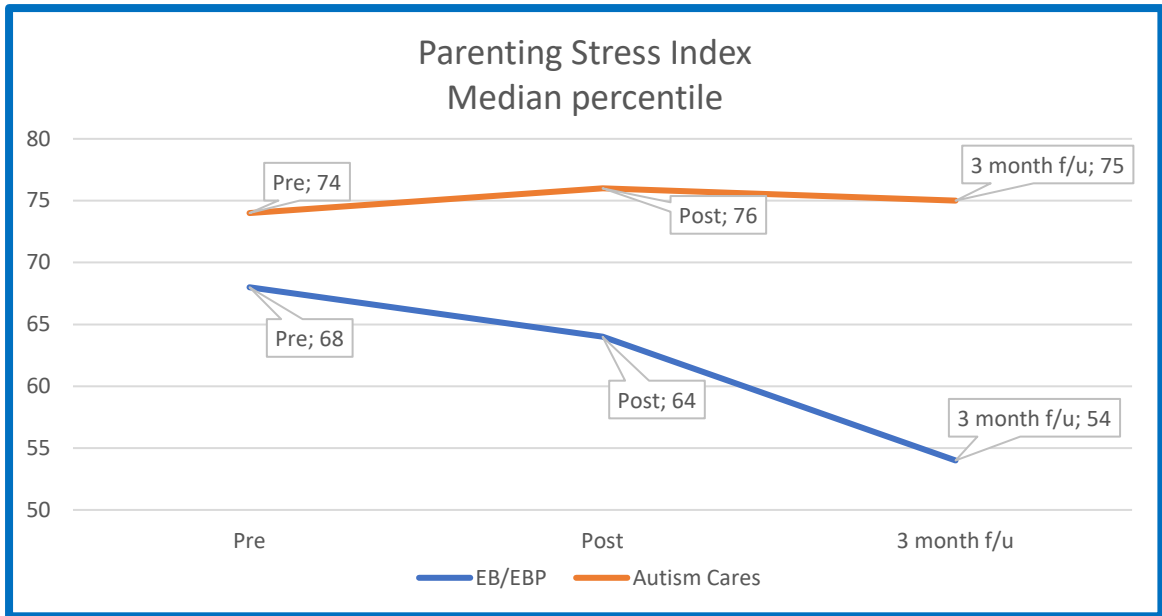
programme) and was not included. As described by Abidin (2012) there are different interpretations or working hypotheses for why a parent might receive a low score on the Defensive Scoring scale. He recommends that caution should be exercised when interpreting such results (Abidin, 2012). It was determined that for the purposes of this research excluding those who recorded such low scores would be preferable to including them as exhaustive exploration as to the reasons for their defensiveness was not logistically feasible.

Child changes on the ATEC (Rimland & Edelson, 1999) were relatively unchanged in the Autism Cares group, but improved by 20 points in the EB/EBP group from 79 at baseline to 59 by 3-months post-course (Figure 5.6). The median pre-programme total score for EB/EBP = 79 (SD = 28.2) and Autism Cares = 80 (SD = 23.09). The post-programme total score for EB/EBP = 71 (SD = 25.34) and Autism Cares = 81 (SD = 12.69). The 3-month follow-up median total score for EB/EBP = 59 (SD = 27.8) and Autism Cares = 77 (SD = 21.05).

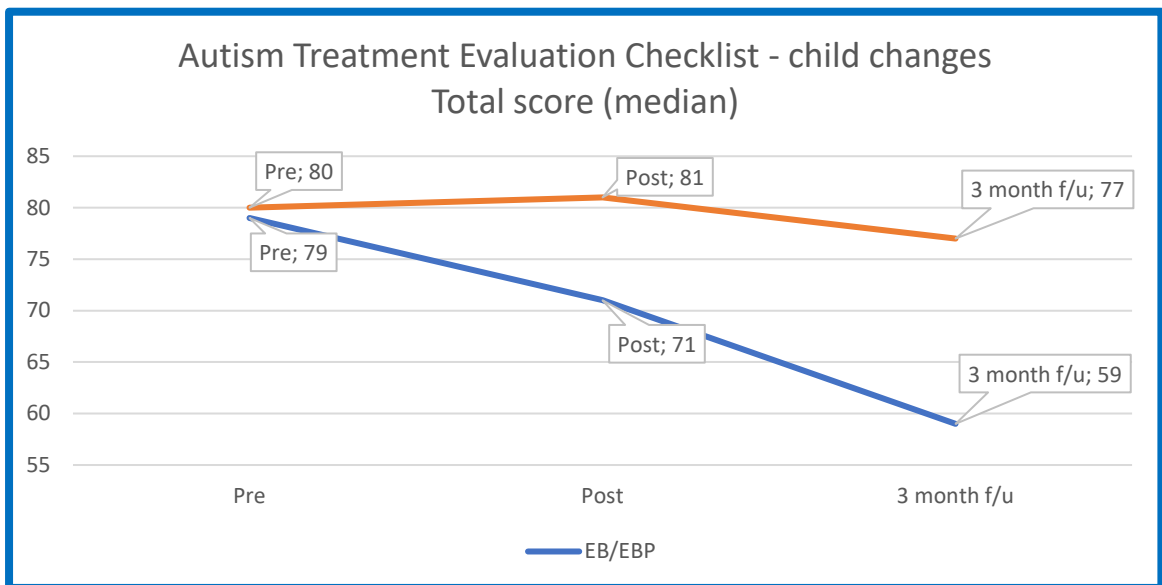
There were missing data at the 3-month follow-up for five participants of EB/EBP and one for Autism Cares.



**Figure 5.4.** Changes in ASD knowledge on the Parent Involvement Questionnaire (Solish & Perry, 2008) in the two groups



**Figure 5.5.** Changes in Parenting Stress Index (Abidin, 1995) in the two groups



**Figure 5.6.** Child changes as on the Autism Treatment Evaluation Checklist (Rimland & Edelson, 1999)

## **Qualitative results**

### Theme 1: Parental Change

#### **EarlyBird/EarlyBird Plus**

Eighty-two separate comments were extracted from the 11 interviews. All of these comments indicated positive changes in the areas of acceptance of the diagnosis (15 comments in 11/11 of the interviews); reduced stress/anxiety (13 comments in 10/11 interviews); increased confidence (20 comments in 9/11 interviews); improved patience (6 comments in 5/11 interviews); increased hope (3 comments in 2/11 interviews); improved understanding of their child (21 comments in 11/11 interviews); more use of strategies they had learnt on the course (13 comments in 10/11 interviews) and talking to others about their child's diagnosis (6 comments in 6/11 interviews).

#### **Autism Cares**

Forty separate comments were extracted from the 10 interviews. All indicated positive changes including acceptance of the diagnosis (1 comment in 1/10 of the interviews); reduced stress/anxiety (8 comments in 8/10 interviews); increased confidence (8 comments in 6/10 interviews); improved patience (3 comments in 3/10 interviews); increased hope (1 comment in 1/10 interview); improved understanding of their child (8 comments in 7/10 interviews) and more use of strategies learnt on the programme (8 comments in 6/10 interviews).

### Theme 2: Child Change

#### **EarlyBird/EarlyBird Plus**

Eight comments were made in 7/11 interviews regarding the positive changes parents had noticed in their child, including general improvement (2 comments in 2/11 interviews); improved behaviour (2 comments in 2/11 interviews); calmer presentation (2 comments in 2/11 interviews) and improved learning (1 comment in 1/11 interview).

#### **Autism Cares**

Three comments in 2/10 interviews reported on child changes. Both parents commented that their children were communicating better than they had before.

### 5.3.3 Multi-stakeholder Panel Consensus Rating using the Evaluation Framework

A total of nine multi-stakeholders participated in the consensus rating and included a child & adolescent psychiatrist, clinical psychologist, an educational psychologist, occupational therapist, two speech and language therapists and a School Deputy Principal. Stakeholders also included a Non-Governmental Organisation (NGO) representative, a health systems researcher and an implementation science researcher. The data available to complete the Evaluation Framework checklist is presented in Table 5.7. A comparison of the two PET consensus evaluations is shown in Table 5.8.

**Table 5.7. Data available to complete the Evaluation Framework Checklist**

<b>Theme</b>	<b>Available data</b>
<b>Outcomes</b>	Parent programme satisfaction measure Semi-structured interview questions Parenting Stress Index Parent Involvement questionnaire Autism Treatment Evaluation Checklist
<b>Processes &amp; Procedures</b>	Semi-structured interview questions Parent programme satisfaction measure Author, NGO and programme presenters' knowledge of the PET programmes, local setting and services
<b>Implementation Landscape</b>	Author, NGO and programme presenters' knowledge of the PET programmes, local setting and services Publicly available data on costs and fees for training and materials

**Table 5.8. Comparative feasibility rating of EarlyBird/EarlyBird Plus and Autism Cares using the ASD PET Evaluation Framework Checklist**

ASD PET Evaluation Framework Checklist			
	EarlyBird/ EarlyBirdPlus	Autism Cares	Comments
<b>Outcomes</b>			
<b>PARENT/CARER OUTCOMES</b>			
1 Is there evidence that the programme leads to an increase in parent/carer knowledge?	Yes	Yes	
2 Is there evidence that the programme enhances beliefs and attitudes of parents/carers?	Yes	Yes	
3 Is there evidence that the programme supports emotional well-being of parents/carers including stress reduction, increasing hope, or managing grief, where applicable?	Yes	More evidence required	There is some level of evidence that EB/EBP provides emotional support and stress reduction though more is required regarding the same areas for AC
4 Is there evidence that the programme increases parent/carer skills that are practical and can be applied in the context of home activities?	Yes	Yes	
5 Is there evidence that the programme leads to increased parent/carer empowerment, confidence, and positive advocacy?	Yes	Yes	
<b>CHILD OUTCOMES</b>			
6. Is there evidence that the programme leads to an improvement in the child's quality of life and well-being?	More evidence required	More evidence required	
7 Is there evidence that the programme leads to changes in parent-specified outcomes (e.g. in specific behaviours)?	More evidence required	More evidence required	While there was some evidence of change in children relating to parent-specified outcomes (particularly for EB/P) both

			programmes require more evidence in this area
8 Is there evidence that the programme leads to changes in ASD-related deficits (e.g. social and communication)?	More evidence required	More evidence required	As above, there was some evidence of change in children (particularly for EB/EBP) though both programmes require more evidence
<b>FAMILY OUTCOMES</b>			
9 Is there evidence that the programme leads to improvement in family quality of life (including siblings)?	More evidence required	More evidence required	
10 Is there evidence that the programme reduces family isolation?	More evidence required	More evidence required	
11 Is there evidence that the programme improves family's access to, getting and mobilisation of support?	More evidence required	More evidence required	
<b>COMMUNITY OUTCOMES</b>			
12 Is there evidence that the programme has a positive impact on the community (e.g. awareness, knowledge and stigma)?	More evidence required	More evidence required	
<b>OVERALL EVALUATION OF OUTCOMES</b>			
Some evidence for both programmes show that there are changes to parent outcomes, although more evidence is required about the effect of the programmes on children, families, and communities. The Evaluation Framework (EF) highlights the need to map outcome measures onto an EF.			
<b>PROCEDURES AND PROCESSES</b>			
<b>ACCESSIBILITY</b>			
13 Is there evidence that the language of the programme is accessible to the target population?	Yes	Yes	Interpreters recommended for both programmes
14 Is there evidence that the location of the programme is accessible to the target population?	Yes	Yes	
15 Is the cost of the programme for the providing organisation/department acceptable?	More evidence required	More evidence required	As part of the research project there was no cost involved for service providers. More evidence would be needed to determine acceptability of

			overall cost, including staff and training cost
16 If there is a cost to the parent/carer for attending the programme is it acceptable to the target population?	More evidence required	More evidence required	As part of the research project there was no cost involved for participants. If a cost was involved, more evidence would be needed to determine acceptability
17 Does the programme require literacy and is there evidence that this will impact accessibility?	Yes	Yes	Both programmes require literacy which may prevent some level of accessibility. More evidence is required to determine to what extent this is a barrier
<b>ACCEPTABILITY</b>			
18 Is there evidence that the programme is culturally acceptable to the target parents/carers?	Yes	Yes	
19 Is there evidence that the programme trainers are acceptable to the parents/carers?	Yes	Yes	
20 Is there evidence that the programme materials are acceptable to parents/carers?	Yes	Yes	
21 Does the programme use a range of modalities to teach (e.g. home visits, experiential learning, video feedback, group discussion)?	Yes	Yes	
22 Is the age range of the programme suitable for the target population?	Yes	More evidence required	Some evidence from the study suggested some parents would have preferred Autism Cares groups to be divided according to age to make the information more relevant
23 Is there evidence that the programmes timeframe is acceptable to parents/carers?	Yes	Yes	
<b>PSYCHOLOGICAL PROCESSES</b>			
24 Is there evidence that the programme psychologically prepares parents/carers of next steps and support after completion of the programme?	Yes	Yes	Both programmes provide some input to prepare participants for next steps. More evidence is required to determine how effective this is.
25 Does the programme structure actively facilitate emotional	Yes	No	It could be argued that both programmes facilitate some level of emotional

containment or parent-to-parent support?			containment. However, EB/EBP structure and format actively focuses on this aspect while Autism Cares does not do so overtly.
<b>REFERRAL PATHWAYS</b>			
26 Is there a clear protocol for referral to the programme?	More evidence required	Yes	While EB/EBP has a clear referral protocol in its manual this has not yet been tested outside of research confines in the local setting
27 Is there evidence that the parents have access to next steps (e.g. step-up interventions as required) after the programme?	Yes	Yes	
<b>OVERALL EVALUATION OF PROCESSES AND PROCEDURES</b>			
Strong acceptability from parents/carers for both programmes. More evidence required for accessibility, psychological processes and referral pathways for both programmes. The overt emotionally containing structure of EB/EBP was commented on as an area of strength.			
<b>IMPLEMENTATION LANDSCAPE</b>			
<b>SUSTAINABILITY</b>			
28 Is there buy-in for the programme from providers, local and national government?	More evidence required	More evidence required	While there is evidence for buy-in from the service provider for Autism Cares, outside of the research none has been established for EB/EBP, both programmes require support from local and national government.
29 Is there evidence that appropriate decision-makers and stakeholders have been included in the implementation of the programme?	More evidence required	More evidence required	As part of the research some decision-makers and stakeholders have been included, though more evidence is required to ensure that they will be included in the future for implementation for EB/EBP and for the continuation of AC
30 Is there evidence that the programme can be sustainable in the intended context?	More evidence required	More evidence required	In its current form Autism Cares has continued since 2014, suggesting it is sustainable, though more evidence will be required to determine this

31. Is there funding for the programme (including proprietary costs)?	No	Yes	There is no funding for EB/EBP outside of the research. There are no proprietary costs for Autism Cares and funding to deliver it is secured through the service provider
<b>INTEGRATION &amp; COORDINATION</b>			
32 Is there integration and coordination of the programme between relevant systems and departments?	No	Yes	Outside of the research project, EB/P has not been integrated/coordinated into relevant local systems. Autism Cares is integrated through the NPO
33 Has there been agreement about who will coordinate, lead and provide oversight for the programme?	No	Yes	Outside of the research no discussion around coordination and oversight of EB/EBP has been established. The NPO provides these roles for Autism Cares.
34. Is there evidence that referrers, professionals and parents/carers are aware of the programme?	More evidence required	More evidence required	While participants and stakeholders in the research were aware, more evidence is required to determine the level of awareness in the broader population outside of this research project
<b>SCALABILITY</b>			
35 Is there evidence that the training can be scaled-up (e.g. is there a train the trainer system)?	Yes	No	
36 Is there evidence that the programme can be replicated across different sites e.g. is it manualised?	Yes	No	The NPO delivering Autism Cares is currently investigating how to manualise the programme.
<b>MONITORING &amp; EVALUATION</b>			
37 Is there evidence of a system to monitor, support and adapt the programme as needed?	Yes	More evidence required	
<b>OVERALL EVALUATION OF THE IMPLEMENTATION LANDSCAPE</b> More evidence required for both programmes regarding sustainability and integration & coordination. EB/EBP shows strengths in the scale-up and monitoring & evaluation components.			

### **OVERALL EVALUATION OF THE PROGRAMMES**

Positive evidence is available for components of both 'Outcomes' and 'Processes and Procedures' though the evidence is not strong and some components do not have any evidence. Evidence for 'Implementation Landscape' is limited, though EB/EBP has some strengths in this theme and was regarded as having strong positive support from the multi-stakeholder panel based on the evaluation.

#### *5.3.3.1 Multi-stakeholder panel consensus*

The consensus multi-stakeholder panel concluded that EB/EBP is a well-thought-out and carefully manualised programme that provides excellent structure to parents while delivering psychoeducation and support. There was reflection that some of the materials may require local adaptation and the difficulty and cost of training trainers was emphasised as a barrier. Autism Cares was described as a well-regarded local programme with good local information, although not as well-developed for parents from a content and structural perspective. The lack of manualisation and programme for training facilitators were regarded as restricting its scope for scalability, in particular. The Evaluation Framework was viewed as a useful tool in evaluating the PET programmes, but panel members emphasised the need to map outcome/evaluation measures onto the Evaluation Framework, in order to improve a panel's ability to rate a PET programme.

## **5.4 Discussion**

In spite of the importance of Parent Education & Training (PET) in ASD, the literature on different PET programmes is relatively limited, and highlighted that – to date – a wide range of outcome measures have been used to evaluate the highly-variable range of programmes. Furthermore, most PET research has focused on efficacy-testing, rather than on other aspects relevant to implementation of PET programmes. To date, the majority of PET programmes have been examined in high-income and high-resource settings, and in the absence of any consensus evaluation framework to judge programmes for specific settings. In this study we therefore set out to compare the feasibility of two ASD parent education & training (PET) programmes in a low-resource LMIC setting, with a focus on acceptability, adaptation and

limited efficacy testing. In addition, we used a newly-generated Evaluation Framework for a head-to-head comparison of these programmes.

The results from parents on both the EarlyBird/EarlyBird Plus (EB/EBP) and Autism Cares programmes showed strong acceptability support for these programmes. These results are largely in line with previous research on both EB/EBP and other PET (Engwall & MacPherson, 2003; Schultz, Schmidt & Stitche, 2011; Cutress & Muncer, 2014; see also chapter 2 and 3). Parents suggested a range of potential adaptations reflective of the needs of multi-cultural settings, such as interpreters in sessions, creating videos with local parents and children, and mixed thoughts about the need to translate materials into primary languages other than English. A range of other individual suggestions for adaptation was also identified and included longer and more sessions, separating parents and professionals, and having information/materials accessible online. Our observations underscore the comments by Guler et al. (2017) who described the importance of context in relation to ASD early intervention programmes in South Africa, specifically commenting on language, culture and location of treatment, amongst others factors. As an example, the wide range of income distribution reported by the study participants is reflective of similar discrepancies in the population of the country and presents a unique challenge to those implementing PET and other interventions in South Africa. While no simple solutions exist ensuring that researchers are familiar with the socioeconomic and sociocultural differences prevalent in the country will be of assistance when considering participant responses and future implementation. Despite these observations, participants were overall very positive that the programmes met their needs in their current form and were relevant and appropriate in a LMIC context. The limited efficacy-testing performed here, showed some positive quantitative pre-post changes in parental knowledge, parental stress and child outcomes, more so in the EB/EBP than in the AC groups. Qualitative parent outcome data were very positive, and suggested some parental perceptions of improved child outcomes. We did not investigate family or community outcomes in this study.

One of the key findings from the multi-stakeholder Evaluation Framework generated for use in this study, was the message that a 'good' PET programme needs to have more than just an outcome-focused evidence-base. Apart from outcomes (for parents, children, families and

the community) and processes/procedures (such as the time, duration, modalities) explored here, the implementation landscape also needs to be considered. For instance, EB/EBP has a highly manualised programme and an excellent trainer system, which are clear facilitators for dissemination and implementation. On the other hand, there is only one training centre for EB/EBP, based in the UK, with significant cost associated with training. Autism Cares has not yet been manualised, and there is currently only one trainer, with no system to train others. The systematic Evaluation Framework Checklist generated in chapter 4 was therefore very helpful in highlighting and comparing the broad range of evaluation components of potential importance in selecting a PET programme for a particular setting.

A unique component of this study was to use a multi-stakeholder panel for a consensus comparison of the two PET programmes examined here. After weighing up all the programme information and mixed-methods data, EB/EBP were deemed to be more suitable for next-step research, given the combination of acceptability, accessibility, efficacy and implementation-related factors such as scalability and sustainability (Milat et al., 2012; Aarons et al., 2017).

If nothing else, the study highlighted the complexity of any comparative study of PET programmes or similar psychosocial interventions in real-life settings. In spite of the importance of PET in ASD, there is clearly much further work required in the research community to generate consensus on key components for evaluation. This includes selecting suitable and widely-usable outcome measures (qualitative and/or quantitative), and considering how to balance the needs of low-resource communities where feasibility studies such as this one may provide richer and more useful initial data prior to randomised controlled trials (Eldridge et al., 2016), whilst ensuring that there is a clear and strong evidence-base – however defined – for a PET programme.

#### *5.4.1 Limitations*

We acknowledge a number of limitations to this study which may reduce the wider generalisation of its findings. First, sample sizes were small and therefore precluded any inferential statistical comparison. However, this allowed for a detailed mixed-method approach which revealed very rich data, particularly in a culturally diverse setting where no such studies had been performed to date. Second, we used a mixture of standardised and

qualitative parental self-report measures to evaluate outcomes, rather than to have performed any independent 'objective' examination of knowledge, change, stress and so on. As raised earlier, there are, however, no consensus measures for the range of potentially-relevant outcomes. For that reason, we opted to use the mixed measures included here. In relation to the increase in knowledge scores it is acknowledged that, although the participant scores increased they did so from a high base and consequently parental self-report may have reflected increased acceptance rather than actual knowledge improvement. The high baseline knowledge scores may also indicate that the questions on the instrument were too easy for this cohort. The selection of a different measurement tool with a more difficult set of questions may have allowed for any possible change in this area to have been captured. This was not a randomised study, and we did not have a control group. However, as a first feasibility step, this did not seem to be the priority. The mixed-method quasi-experimental approach used, revealed a range of challenges to consider for future studies. For logistical and practical reasons and as outlined in Table 5.8 we did not have data available on all of the evaluation frameworks criteria. For this reason, a comprehensive comparison of the two programmes was not possible and is a limitation of the study. Despite this we believe the comparison done has provided a useful indication of the programmes strength and weaknesses. A limitation of this study was that the analysis of the data was done primarily by the first author. Although there was consultation with the co-author to prevent bias this approach will have increased the potential for same.

## **5.5 Conclusion**

There is clear global recognition of the value in PET for ASD. However, the evidence-base for PET programmes has been limited to date, and no evaluation framework existed. In this study we compared two very different PET programmes, one widely-used internationally, but not in South Africa, the other developed in South Africa, but never previously evaluated. We examined the acceptability, adaptability and performed limited efficacy-testing and identified strengths and weaknesses of both. Applying a recently-generated ASD PET Evaluation Framework (EF), a multi-stakeholder panel concluded that both programmes had important strengths, though particularly emphasised factors relating to processes & procedures and the

implementation landscape which will impact their scalability and sustainability. In addition, the panel concluded that the EF could have real value for the evaluation of other ASD PET programmes, and potentially for ASD interventions more broadly. Despite the limitations of this comparative feasibility study, it highlighted the need, and sets the scene, for further work on parent/carer education & training for Autism Spectrum Disorder.

## **5.6 Chapter summary**

In spite of the need for post-diagnostic parent/carer education and training (PET) in ASD, the research evidence-base is relatively-small, particularly in Low-and-Middle-Income Countries (LMIC). A wide range of programmes exist, but with no consensus on criteria to evaluate such programmes for implementation in culturally diverse settings.

Here we performed a comparative feasibility study of two PET programmes in a low-resource setting. EarlyBird/EarlyBird Plus (EB/EBP), a UK-developed, widely used and highly manualised 12-week programme was compared to Autism Cares, a locally-developed 5-day programme. Our two aims were first, to examine acceptability, adaptation and perform limited efficacy testing of the programmes; second, to use a newly-generated multi-stakeholder ASD PET Evaluation Framework to compare them.

A mixed-method, quasi-experimental design was used to collect pre, post and 3-month follow-up data. Measures included standardised and custom-designed quantitative outcome measures (e.g. Parenting Stress Index, Autism Treatment Evaluation Checklist, Parent Involvement Questionnaire, and Parent programme satisfaction measure) and qualitative semi-structured interview data.

Eighteen parents participated in the EarlyBird/EarlyBird Plus programmes, and eleven in the Autism Cares programme. Parent/carer and child characteristics were very similar. In particular, at least 30% of families earned <\$300 per month. Strong parental acceptability for both programmes was found along with the need for some adaptations to the local context.

Limited efficacy testing showed positive changes for parental stress, knowledge of ASD and changes in child, more so for EB/EBP than AC. The multi-stakeholder panel acknowledged strengths and weaknesses of both programmes, but judged EB/EBP as most suitable for next-step research citing factors relating to implementation including scalability and sustainability.

Our findings contributed to the limited evidence-base for ASD PET in low-resource environments but highlighted the need for global collaboration to identify consensus measures to include in future research. The ASD PET Evaluation Framework provided a useful structure for comparison of the two programmes, but emphasised the need to align measures with the evaluation criteria. Overall, the study underlined the need for the evidence-base of ASD PET programmes to include processes & procedures, and examination of the implementation landscape, in addition to outcomes.

# Chapter 6

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## Conclusion

### 6.1 Thesis summary

Autism Spectrum Disorder (ASD) is now recognised as a global public health concern. By definition, this means that ASD is seen in all countries. It is, however, well-accepted that even though most people with ASD live in Low- and Middle-Income Countries (LMIC), most ASD research to date has been performed in High-Income Countries (Elsabbagh et al., 2012; Abubakar et al., 2016; de Vries, 2016; Franz et al. 2017). The same discrepancy applies to Parent Education & Training (PET), the placeholder term used in this thesis to refer to the passing on of information or skills to parents/carers using a range of modalities. Even though PET could be clinically invaluable particularly in LMIC and other low-resource environments, the research focus on PET in LMIC has been limited.

In this thesis, we were therefore interested to explore PET programmes in a systematic way with a broad implementation science lens, to shed light on PET programmes that may be suited to lower-resource settings such as in LMIC.

The thesis had four specific aims. We firstly set out to complete a scoping review of the evidence relating to the EarlyBird and EarlyBird Plus Parent Education & Training (PET) programmes developed by the UK National Autistic Society. EB/EBP were selected very pragmatically since they were programmes that had been run in clinical settings in the UK for many years and with good general feedback. The author and thesis supervisor had both worked in the UK and were therefore familiar with these programmes. Given our 'low resource-centric' interest, we were interested not only in the outcomes-based evidence, but also in the implementation-based evidence. Our second aim was to understand and describe the broader landscape of PET programmes over and above EB/EBP. We anticipated that this broader review would give a sense of the overall 'state of the art' of PET research. The key

goal of the thesis was to perform a comparative study between two PET programmes in a representative South African setting where families would be predominantly low-resourced and multi-cultural. Working through aims 1 and 2 brought the realisation that the PET literature had no existing evaluation frameworks that would support us in that key aim. We therefore created, as a third aim, an ASD PET Evaluation Framework and Checklist. The fourth aim was then to employ a mixed-methods implementation science approach to compare the feasibility of these two PET programmes, EarlyBird/EarlyBird Plus and Autism Cares, in South Africa.

The comprehensive scoping review of EB/EBP was presented in chapter 2. Despite having been attended by over 27000 families in 14 countries, the review indicated the evidence-base for the programme, whilst positive, was of limited strength and quality. Only 18 articles were found (16 from the UK and 2 from New Zealand) and only one used a control group. The lack of randomised controlled designs and small sample sizes limited generalisation of findings. When investigating implementation elements, only a few aspects including acceptability and limited efficacy-testing had been examined. Many other aspects such as demand, expansion, and fidelity, were rarely commented on. The review recommended more research on the programmes from outside the UK, particularly in LMIC settings and with a focus on feasibility wherever possible. Larger and controlled studies were also recommended to increase the generalisability and evidence-base of the programme.

In chapter 3 we then expanded the review to research on all PET programmes outside the USA. We followed a rigorous review procedure, led by the author and supported by 3 independent coders. The review established several important conclusions after extracting and reviewing data from the 37 identified publications. Research from 20 different countries on 34 unique PET programmes met inclusion criteria and detailed a wide range of PET programmes implemented globally. While the majority were either group-based (51%) or a combination of individual and group-based (31%), many of the programmes had several aims over and above the transfer of knowledge (e.g. reduction of parent/carer stress, passing on of behavioural strategies), and used multiple modalities to deliver the programmes. In spite of the importance of PET and the need for investigation to establish efficacy and feasibility, research in this growing field is relatively limited and the majority of published work reviewed

used quasi-experimental study designs (64.8%) with only 5 publications using Randomised Controlled Trial (RCT) design. The wide range of outcome measures used, further limited comparison of the programmes and generalisation of the research findings. Despite the delivery in such a variety of countries there was little focus in the research on factors relating to implementation (e.g. fidelity, cost, impact of cultural aspects). The broader review results were therefore very consistent with those of the EB/EBP findings. The review recommended inclusion of factors relating to implementation (e.g. acceptability, cost, culture, scalability, replicability) and the need for standardised outcome measures, larger samples, and RCTs.

Given the absence of any suitable Evaluation Framework for PET in the current literature, we used a participatory research strategy to generate a framework that could be employed to evaluate, compare and contrast PET programmes, as set out in chapter 4. An implementation science methodology included the recruitment through purposive sampling of 14 stakeholders from a range of disciplines and roles with appropriate expertise and experience in ASD and research in low-resource environments to participate in the process. Consensus-building multi-stakeholder workshops, facilitated by the author, enabled the development and refinement of an ASD PET Evaluation Framework and Checklist. The consensus framework included three main themes – ‘Outcomes’, ‘Processes & Procedures’ and ‘Implementation Landscape’. Under each of these themes additional components and criteria were outlined. The framework and its development emphasised the need to consider factors over and above outcomes and efficacy. We used the image of three inter-linked cogs to create a visual representation of the importance of all three themes. The multi-stakeholder panel proposed that the framework could be used to provide guidance to a range of groups including clinicians, researchers and policy makers to determine which programme would suit their contexts and needs best.

Acknowledging the high need and the absence of any research on PET programmes in South Africa, the thesis concluded in chapter 5 with a comparative feasibility study of two PET programmes – EarlyBird/EarlyBird Plus (EB/EBP) and Autism Cares, a locally-developed PET programme. Using Bowen et al’s (2009) theoretical constructs of feasibility, a mixed-method approach was used. Twenty-nine participants were recruited and took part in either EB/EBP (n = 18) or Autism Cares (n = 11), ran sequentially in Cape Town (South Africa). Parents all had

children with a diagnosis of ASD. A combination of qualitative and quantitative measures was used at three time points – baseline, end-of-programme, and 3-months post-programme. Standardised, custom-designed and semi-structured interview data were used to evaluate acceptability, adaptation and limited efficacy-testing. In addition, the previously generated Evaluation Framework was used by a multi-stakeholder panel to compare and contrast the two programmes. The results indicated there was strong acceptability from parents for both programmes. A range of suggestions for adaptations to a South African context were provided and limited efficacy testing showed positive albeit limited evidence for changes in outcomes.

Evaluation of the two programmes by the multi-stakeholder panel highlighted the importance of processes & procedures and the implementation landscape in addition to outcome-focused evidence. EB/EBP were regarded as highly manualised programmes with excellent trainer systems. The significant cost of training facilitators was, however, noted as a significant barrier to implementation. The lack of manualisation of Autism Cares was viewed as a hindrance to replicability and fidelity. In view of the comparative analysis EB/EBP was regarded as more suitable for future research and implementation. The complexity of comparative study in real-life settings was also highlighted and to this end the importance of feasibility studies, in addition to randomised control trials, particularly in low-resource settings, was emphasised.

In spite of the acknowledged and stated need for PET programmes in ASD, the findings from this thesis suggest that the PET research is still at a relatively early stage. The fact that we were able to identify only 18 EB/EBP publications and 37 overall underlines our observation. In recent years, significant attention has been focused on ‘parent-mediated interventions’ such as the range of Naturalistic Developmental Behavioural Interventions (e.g. Early Start Denver Model, Pivotal Response Training, Enhanced Milieu Training, JASPER), where the emphasis is on work with the parent-child dyad (Koegel et al., 1999; Kasari, Freeman & Paparella, 2006; Kaiser & Trent, 2007; Rogers & Dawson, 2009). In contrast, parent education & training had perhaps fallen behind, or perhaps never had a strong research-based start. In Low- and Middle-Income Countries, in particular, we propose that PET programmes may have immense potential to empower parents/carers, families and communities. The thesis therefore raises the need for a significant increase in research efforts in PET.

Apart from the key need for PET research, the other main finding of this thesis was the recognition of the importance of implementation science in ASD research. The need for this kind of research in LMIC and other low-resource contexts is particularly pertinent where determining, for instance, which PET programme would be most appropriate given contextual needs (e.g. culture, language, accessibility, financial and other aspects). ‘Outcome-focused’ research and its predilection towards the “gold standard” RCT have been the primary focus of the majority of ASD intervention research to date, and is considered the ‘evidence-base’. This thesis contends that, while necessary, the evidence-base for a programme should also include information relating to processes & procedures and the implementation landscape. Evidence of good outcomes is a necessary, but not sufficient step in ASD intervention research. The generation and use of the Evaluation Framework used to compare the two PET programmes in South Africa underscored the importance and complexity of examining such factors in real-world settings.

## **6.2 Limitations**

The thesis has a range of limitations which were acknowledged in the chapters. We also acknowledge some broader limitations here. Firstly, our review of the global literature used the hybrid term ‘Parent Education & Training’ which had not been employed previously. The term may therefore have discounted programmes/interventions included under the broader term of ‘Parent Training’ as proposed by Bearss et al. (2015). However, we felt that the hybrid term was perhaps more in keeping with a number of programmes currently available, including the new WHO Caregiver Skills Training (CST) programme which combines ‘parent training’ with ‘skills training’. The CST is currently being developed and is being piloted around the world. It has a broad scope to include parents and carers of those with ASD in addition to those with neurodevelopmental ‘red flags’ but without a diagnosis. It has received positive early feedback from facilitators and participants indicating both strong early acceptance and the high level of need and demand for these kinds of programmes (WHO, 2015). The pragmatic proposal to focus on the participants – parents/carers versus the parent-child dyad seemed a useful solution to us.

We acknowledge that the ASD PET Evaluation Framework was generated using a predominantly South African stakeholder group. Whilst this was done to provide meaningful information for the local context, it may – as a result – have missed out on other aspects of PET evaluation. However, we aimed to include experts with broad experience in both LMIC and HIC, as well as representative parents and sibling participants were specifically included to minimise this potential bias and create a framework for global use. It is hoped that future evaluation of the framework in other contexts will further refine the framework to determine its global applicability. Similarly, the study was conducted in a single geographical location in one LMIC country. We therefore acknowledge that there may be many important implementation factors that did not emerge as a result. However, given the highly multi-cultural nature of South Africa and the great health disparities seen in the country, we are confident that this thesis will at least have captured some universal findings to inform global next steps in ASD PET research.

### **6.3 Future Directions**

Based on the findings of this thesis, six recommendations for next steps are given:

First, the expansion of local PET research in South Africa. This would ideally include larger samples as well as multi-site research designs. The addition of control groups and the inclusion of more cultural diversity in the samples would also be beneficial. As described in chapter 3 there is some though relatively limited evidence-base for PET. The evidence presented in chapter 5, including parent/caregiver acceptability and factors relating to processes & procedures and the implementation landscape, indicates that there is a basis for continuing with further research of EB/EBP in South Africa. There are currently no pre-defined or agreed upon levels of evidence to determine when a programme should be studied further or scaled out. For example, the recently developed WHO Carer Skills Training does not have an evidence base in South Africa though this clearly should not exclude it from early stage research in the country. Future research may seek to determine what levels of evidence are required for a programme to warrant expansion or further study.

Second, further evaluation of the framework checklist by external stakeholders, including research groups and service providers, would strengthen information on its utility and provide recommendations for adaptations or augmentations. This may allow for a global consensus on a ASD PET framework. The development of an accompanying document to assist users in how to engage with the framework and specifically select and obtain relevant data would also be of value. Insights from other models (e.g. PASSING) could be valuable in the production of such a document.

The creation of standardised outcomes for PET programmes through the involvement of global stakeholders is recommended. As reported in chapter 3 there are multiple measures used by researchers making comparison between research challenging. Consensus on appropriate instruments that can be used across settings in a valid and reliable manner would assist greatly in advancing research in PET and allow for a strengthened and more cohesive body of evidence.

The dissemination of PET findings and the lobbying of potential funders will ensure awareness around the importance of research in this area. As described in chapter 2 and 3 there is relatively little awareness and research in the area of PET, despite the clear need. Ensuring that relevant research and findings are disseminated will raise the profile of this important area. Ensuring that funding is sourced for broader and more systematic research will be critical in encouraging researchers to focus on the area.

Caution should be exercised regarding the implementation of any PET programmes that do not have an appropriately robust evidence-base. Such an evidence-base should include outcomes-based data as well as implementation-based evidence. The broader field of PET and the scoping review completed indicates that despite such a limited evidence-base there are many programmes being implemented around the world. The strong need for such programmes suggests that researchers will need to work in partnership with stakeholders to create relevant and timeous research.

With the growing interest and research in this area, the setting up of a global PET network may be timely. Such a global PET network may ensure collaborative and joined-up working in

this important field of ASD research and could lead to global consensus guidelines for researchers, policy makers and service providers. Such a network should be aligned with the needs of those stakeholders and work collaboratively towards appropriate goals. There could also be scope within that network for lobbying and research partnerships that create funding opportunities with larger samples and so create a larger evidence-base.

## **6.4 Conclusion**

We set out on this project to evaluate the evidence for PET programmes in ASD. We expected to identify a research-base for PET programmes that would be relatively mature and well-established in High-Income Countries, but weak in Low- and-Middle-Income Countries. In contrast to our predictions, we discovered that the global evidence-base for PET programmes is still quite immature, and that relatively little PET research has been conducted anywhere. The multi-stakeholder process, in particular, helped us to recognise the complex interactions between outcomes, processes & procedures and the implementation landscape. Notwithstanding the small scale of our comparative feasibility study, we were encouraged by the overwhelmingly positive feedback from parents/carers. In spite of the limitations, our early steps to generating a local evidence-base for PET programmes has motivated us to explore next steps in scale-up and scale-out of these programmes. We sincerely hope that the findings from this thesis will be of value to other researchers in the field, particularly those who also work in low-resource environments.

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## **Appendix A**

### **Multi-stakeholder workshop questions**

#### **Individually & small groups**

- 1) In a South African context what would you want from an ASD specific parent programme shortly after diagnosis?
- 2) What barrier/challenges/problems do you foresee with implementing (and scaling up) such a programme?

#### **Large group**

- 3) What factors are important for an ASD specific parenting programme in South Africa shortly after diagnosis?
- 4) Can you prioritise these factors? If so, which of them would you consider essential, important, or 'nice to have'?

## Appendix B

### Demographic questionnaire

In this questionnaire we will ask you some questions to understand your families current circumstances. Please answer them to the best of your ability. If you have any questions please ask the researcher for assistance.

**1. Age**

18-29

30-39

40-49

50+

**2. Gender**

Male

Female

**3. Race**

Black

Coloured

White

Indian

**4. Religion/Culture**

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**5. Home language**

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**6. Currently Married**

Yes

No

**7. Location of residence**

Urban

Rural

**8. Postal code of residence**

**9. Number of people living at home**

1      2      3      4      5      6+

**10. Education**

None  
Grade 1-7  
Grade 8-11  
Completed High School  
Post High Education

**11. Employed**

Yes  
No

**12. Monthly household income**

None  
R1-5000  
R5001 – 25000  
R25001 – 100000  
R100000+

**13.** We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement. Circle the "1" if you Very Strongly Disagree Circle the "2" if you Strongly Disagree Circle the "3" if you Mildly Disagree Circle the "4" if you are Neutral Circle the "5" if you Mildly Agree Circle the "6" if you Strongly Agree Circle the "7" if you Very Strongly Agree

1. There is a special person who is around when I am in need. 1 2 3 4 5 6 7 SO
2. There is a special person with whom I can share my joys and sorrows. 1 2 3 4 5 6 7 SO
3. My family really tries to help me. 1 2 3 4 5 6 7 Fam
4. I get the emotional help and support I need from my family. 1 2 3 4 5 6 7 Fam
5. I have a special person who is a real source of comfort to me. 1 2 3 4 5 6 7 SO
6. My friends really try to help me. 1 2 3 4 5 6 7 Fri
7. I can count on my friends when things go wrong. 1 2 3 4 5 6 7 Fri
8. I can talk about my problems with my family. 1 2 3 4 5 6 7 Fam
9. I have friends with whom I can share my joys and sorrows. 1 2 3 4 5 6 7 Fri
10. There is a special person in my life who cares about my feelings. 1 2 3 4 5 6 7 SO
11. My family is willing to help me make decisions. 1 2 3 4 5 6 7 Fam
12. I can talk about my problems with my friends. 1 2 3 4 5 6 7 Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO)

ADAPTED FROM MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT (ZIMET, DAHLEM, ZIMET & FARLEY, 1988).

## **Appendix C**

### **Semi-structured Interview Questions**

#### **Pre-programme**

Could you describe your child, including what and how they are currently doing?

Could you describe a typical day with your child?

When was your child diagnosed with ASD?

What are your current concerns regarding your child?

What three things would you most like to change about your current situation?

What support have you got up to this point?

What services are available that you are aware of for parents of children with ASD?

What are you hoping for from this course?

How do you feel it will alter your day to day life?

Would you like to add anything else to this interview or make further comments?

## Post-programme

How did you find the programme?

Did the programme meet your needs (expectations)?

What did you take away or learn from the programme?

What were the most helpful areas of the programme?

What and how would you change the programme to make it most helpful to parents?

Home visits

Transport

Video's

Facilitators/presenters

Parent book

Content

Way it was taught (different modalities)

Is there anything about the programme that was not helpful?

How have you changed the way you interact with your child, how has it affected your day to day life?

How has the programme affected your family? (telling other family members)

Were there some areas you would add to the course?

Practicalities – any changes to length of the programme, length of the sessions, day/time it was run?

How has it affected your understanding of ASD, including confidence, stress, support?

Did you feel it was appropriate/relevant/helpful for yourself, other South African parents?

Do you feel this training is needed in South Africa?

Have you become aware of other ASD services/schools for your child or yourself during programme?

How will this change what other services you access?

What do you think about having professionals on the programme?

What do you think about having different ages on the programme (e.g. younger, older, all)?

When is the best time to do the programme (e.g. before diagnosis, straight after, long after, doesn't matter)?

Would you pay for the programme?

Would the programme be better with South African adaptations/additions/changes/ or translations?  
Could you make some suggestions?

What are the steps going forward for you, your family and your child? How do you think the future will be?

Would you like to add anything else to this interview or make any more comments?

## Appendix D

### Examples of questions from the Parent Involvement Questionnaire

Parents are asked to circle either 'True' (T) or False (F). They are encouraged to make their best guess though if completely unsure of an answer may circle 'Don't Know; (DK).

1. Autism is an extremely rare disorder. T F DK
2. The earliest signs of autism include poor response to being called by name and lack of pointing. T F DK
3. Children with autism do not always, but may, have intellectual disability. T F DK
4. Children with autism range from being nonverbal to being verbal. T F DK
5. Children with autism usually engage in play that looks like that of other children their age. T F DK

# Appendix E

## Ethical Approval - HREC



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](mailto:sumayah.ariefdien@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

03 March 2016

**HREC REF: 007/2016**

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

Dear Prof de Vries

**PROJECT TITLE: EDUCATION AND SKILLS TRAINING FOR PARENTS OF CHILDREN WITH AUTISM IN SOUTH AFRICA: FEASIBILITY OF THREE TRAINING PROGRAMMES (PhD Candidate - JJ Dawson-Squibb)**

Thank you for your response letter dated 22 February 2016, 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 30 March 2017.**

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](http://www.health.uct.ac.za/fhs/research/humanethics/forms))

***We acknowledge that the following student, John-Joe Dawson-Squibb will also be involved in this study.***

**Please quote the HREC REF in all your correspondence.**

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

Yours sincerely

*Tuburges*  
PP **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 Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

HREC 007/2016

Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.

The Human 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.

HREC 007/2016



**FHS016: Annual Progress Report / Renewal**

HREC office use only (FWA00001837; IRB00001938)		
This serves as notification of annual approval, including any documentation described below.		
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date 30.3.2019
<input type="checkbox"/> Not approved	See attached comments	
Signature Chairperson of the HREC		Date Signed 7/2/2018

Comments to PI from the HREC

**Principal Investigator to complete the following:**

**1. Protocol Information**

Date (when submitting this form)	5.2.2018		
HREC REF Number	007/2016	Current Ethics Approval was granted until	March 2018
Protocol title	Education and skills training for parents of children with autism in Africa: Feasibility of three training programmes		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Professor Petrus J de Vries		
Department / Office Internal Mail Address	Psychiatry and Mental Health Division of Child & Adolescent Psychiatry, 46 Sawkins Road, Rondebosch, 7700		

## Appendix F

### Study information sheet and informed consent form

#### Study information sheet and informed consent form

#### **STUDY TITLE: FEASIBILITY OF THE EARLYBIRD PROGRAMME IN SOUTH AFRICA**

Hello and thank you for reading this information. Under the supervision of Professor Petrus de Vries, and as part of a PhD research project we are doing a study to find out how the EarlyBird programme will work in South Africa. The EarlyBird is a programme designed for parents of children who have a diagnosis of Autism Spectrum Disorder. The course is designed to provide information for parents about Autism and gives strategies and practical ideas about ways of supporting communication, socialising and behaviour. The programme also aims to provide support, reduce stress and improve confidence.

A maximum of 6 families (two parents per family) can attend the course. The group is run over eight weekly two and a half hour sessions. In addition, the course facilitators will do scheduled home visits to support parents and provide individual input. The course is run on a Saturday between 9am and 11h30.

The group has been run successfully in many countries around the world and has been attended by over 13000 families. This is the first year it has come to South Africa. A pre-pilot of the course was run earlier in the year and the parents who attended were very positive about its potential and all indicated they would recommend other parents to attend.

**What do we want to know?** We would like to know if this programme is helpful, applicable and appropriate for South African parents. To do this we would like to invite parents who have children under the age of four with Autism to participate in the programme. Before and after the course we would like to interview you to find out what your current concerns are regarding your child, what services you access and what your hopes are from the course. After the course we would like to know if you found it helpful and if it met your expectations. We would also like to know what changes you would suggest to make sure it is relevant and applicable for local parents.

As the EarlyBird programme and the parent manual is in English, you will need to understand and speak English as one of your languages to take part in the study.

**What would I need to do?** If you decide to take part in this study, you will be asked to do a number of things:

1. Read the information sheet and sign the consent form
2. Fill in some questionnaires & take part in an interview before the group starts. Once you have agreed to take part in the group you will be contacted and an interview will be arranged at a venue that is convenient for you.
3. Attend the group (we will be able to pay R100 per session per family to cover transport costs)
4. Fill in some questionnaires and do interview after the group. Again, following the group you will be contacted and an interview venue will be arranged.
5. We will also be doing some short observations of you interacting with your child before and after the course (around 10mins). These will be videoed for the purposes of the study and later destroyed.

**Are there any risks or benefits for me?** There are very limited risks to taking part in this study. Some parents may feel some distress in describing their current circumstances during the interviews, if this does occur it will be dealt with sensitively and professionally by the interviewer. Referral to appropriate support services can be arranged for parents should they desire. There are some benefits for you if you decide to take part: you will attend a twelve-week course specifically designed for parents of children with ASD that has been well researched and given positive feedback by thousands of parents around the world. You will receive a parent manual that comes with the course with all the parent information on the programme which you can keep. You will meet up with other parents who also have children with ASD around the same age. In the unlikely event that any medical emergency arises during the programme these will be dealt with as appropriately by the programmes facilitators.

**Who will know what I say? (Confidentiality).** Your suggestions and opinions about the programme will be compiled into a research report. However, your name will not be included i.e., the information will be reported anonymously. You will need to sign your name on the consent form, but your name will not be used on any other forms, just a number.

**Can I refuse to take part or withdraw?** Yes. Taking part is voluntary. There are no problems for you if you don't take part and you can withdraw from the study if you change your mind. Refusal to take part in this study will not affect your current or future health care.

**Ethical approval.** This study has ethical approval from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, protocol number 007/2016.

**Questions.** If you would like more information about this study, please call the project coordinator John Joe Dawson-Squibb at [john-joe.dawson-squibb@uct.ac.za](mailto:john-joe.dawson-squibb@uct.ac.za) or 021 6854103. The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case you have any questions regarding your rights and welfare as participants in this study.

## Consent Document for Participants

- I have been informed about the nature, purpose and procedures of the study entitled “Feasibility of EarlyBird programme in South Africa”.
- I have also received, read and understood the written information about the study.
- I understand that the results of the study, including my opinions regarding the feasibility of the programme, will be reported in a study report and that this information will be kept confidential and anonymous.
- I understand that the data collected during this study will be kept in a password protected computerised system.
- I agree to video recording of an interaction with me and my child that will be used for the purposes of this study and will also be kept in a password protected computerised system.
- I understand that I am free to withdraw from the study at any time.
- I have understood everything that has been explained to me and I consent to take part

---

Printed Name

Signature

Date and Time

## Study information sheet and informed consent form

### STUDY TITLE: FEASIBILITY OF THE AUTISM CARES PROGRAMME IN SOUTH AFRICA

Hello and thank you for reading this information. Under the supervision of Professor Petrus de Vries, and as part of a PhD research project we are doing a study to find out about the feasibility of the Autism Cares programme in South Africa. The course is designed to provide parents and professionals with information about Autism as well as giving strategies and practical ideas about supporting development, socialising and behaviour.

The programme is run over four days and each day covers different areas, i.e. 1) Understanding Autism 2) Behaviour management 3) Early learner therapy 4) ASD and inclusion in education. The course is run by Autism Western Cape, a not for profit organisation based in Cape Town.

This is part of a broader study that is looking to compare three such parenting programmes with each other to assess how best they can be adapted for a South African population.

**What do we want to know?** We would like to know if this programme is helpful, applicable and appropriate for South African parents. To do this we would like to invite parents who have children with Autism to participate in the programme. Before and after the course we would like to interview you and give you some questionnaires to complete. In the interview before the course we would like to find out what your current concerns are regarding your child, what services you access and what your hopes are from the course. After the course we would like to know if you found it helpful and if it met your expectations. We would also like to know what changes you would suggest to make sure it is relevant and applicable for local parents.

As the programme is designed in English, you will need to understand and speak English as one of your languages to take part in the study.

**What would I need to do?** If you decide to take part in this study, you will be asked to do a number of things:

1. Read the information sheet and sign the consent form
2. Fill in some questionnaires & take part in an interview before the group starts. Once you have agreed to take part in the group you will be contacted and an interview will be arranged at a venue that is convenient for you.
3. Attend the group (we will be able to pay R100 per session per family to cover transport costs)
4. Fill in some questionnaires and do an interview after the group. Again following the group you will be contacted and an interview venue will be arranged.
5. We will also be doing some short observations of you interacting with your child before and after the course (around 10mins). These will be videoed for the purposes of the study and later destroyed.

**Are there any risks or benefits for me?** There are very limited risks to taking part in this study. Some parents may feel some distress in describing their current circumstances during the interviews, if this does occur it will be dealt with sensitively and professionally by the interviewer. Referral to appropriate support services can be arranged for parents should

they desire. There are some benefits for you if you decide to take part: you will attend a four day course specifically designed for parents of children with developmental disabilities. You will receive all the programme information that comes with the course which you can keep. You will meet up with other parents who also have children with developmental disorders around the same age. In the unlikely event that any medical emergency arises during the programme these will be dealt with as appropriately by the programmes facilitators.

**Who will know what I say? (Confidentiality).** Your suggestions and opinions about the programme will be compiled into a research report. However, your name will not be included i.e., the information will be reported anonymously. You will need to sign your name on the consent form, but your name will not be used on any other forms, just a number.

**Can I refuse to take part or withdraw?** Yes. Taking part is voluntary. There are no problems for you if you don't take part and you can withdraw from the study if you change your mind. Refusal to take part in this study will not affect your current or future health care.

**Ethical approval.** This study has ethical approval from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, protocol number \*\*\*\*\*.

**Questions.** If you would like more information about this study, please call the project coordinator John Joe Dawson-Squibb at [john-joe.dawson-squibb@uct.ac.za](mailto:john-joe.dawson-squibb@uct.ac.za) or 021 6854103. The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case you have any questions regarding your rights and welfare as participants in this study.

## Consent Document for Participants

- I have been informed about the nature, purpose and procedures of the study entitled “Feasibility of the Autism Cares programme in South Africa”.
- I have also received, read and understood the written information about the study.
- I understand that the results of the study, including my opinions regarding the feasibility of the programme, will be reported in a study report and that this information will be kept confidential and anonymous.
- I understand that the data collected during this study will be kept in a password protected computerised system
- I agree to video recording of an interaction with me and my child that will be used for the purposes of this study and will also be kept in a password protected computerised system.
- I understand that I am free to withdraw from the study at any time.
- I have understood everything that has been explained to me and I consent to take part

---

Printed Name

Signature

Date and Time