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PARENTAL SELF-EFFICACY

The weight of waiting: the impact of delayed early intervention on parental self-efficacy

Kerry Murphy and Emily Harrison

Early intervention is a systematic approach for identifying and co-ordinating support for children up to five years of age with developmental delay. The increasing number of children needing early intervention is leading to longer waiting lists for assessment, treatment and diagnosis. Through a mixed-methods approach, this study examined the impact of waiting lists on parental self-efficacy (PSE). An online survey was completed by 197 mothers of children with special educational needs aged one to seven years. Six mothers later took part semi-structured interviews. The research aimed to establish (a) whether there was a relationship between length of time on waiting lists and PSE, and (b) whether there were specific themes or patterns associated with delayed early intervention and PSE. Results showed no significant relationship between time spent on a waiting list and perceived PSE. The qualitative results, however, found that limited contact and poor quality of interactions alongside a lack of information did reduce perceived PSE.

Key words: **early intervention, self-efficacy, special educational needs, parenting, waiting lists**

Early intervention is defined as a systematic approach for identifying and coordinating support for children up to five years of age with developmental needs (Mahoney & Wiggers, 2007). The general premise is that by intervening at the earliest stage, a further manifestation of delay can be alleviated, providing the child with greater opportunities to secure positive life outcomes (Irwin et al., 2007). Many parents must first engage with universal services

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before graduating onto targeted or specialist support (Falkus et al., 2016). If developmental concerns are identified, early intervention services offer a range of universal therapies; for example, NHS-funded speech and language therapists provide a behavioural intervention (Thomas, 2017) known as Parent-Child Interaction Therapy (PCIT).

Early intervention is reliant on collaborative working across services (DfE & DHSC, 2015; Tutt & Williams, 2015), and this process of working together should ensure that parents and professionals collaborate to create a holistic and shared understanding of the child's needs (Hodkinson, 2015). When effective, it has been found to have benefits for the child (Dunst et al., 2007), for example, by enhancing their potential for independence in adulthood (Bailey et al., 2006). Parents also benefit from early intervention: when they are knowledgeable about their child's needs, they experience an increase in parental empowerment, and increased parental self-efficacy (PSE) (Barlow et al., 2002). Equipping parents with information about their child's special educational needs or disability is also a positive coping strategy for parents (Pain, 2001).

One way in which parents have been prepared for intervention has been through parent-led therapies, which have been shown to impact positively on children's outcomes and reduce parental frustration and stress (Oono et al., 2013). If equipped by professionals who can teach the parent new skills, the parent becomes their child's leading early interventionist, nurturing a synchronous relationship that helps the child to progress (Siller & Sigman, 2008). Trained therapists will usually demonstrate a technique or strategy, guide parents, and set 'homework', and parents are then encouraged to embed these techniques into everyday experiences and routines (Strauss et al., 2012). According to Connolly and Gersch (2013), however, parents do not access this in a timely manner, and describe the wait for therapy as the most stressful part of early intervention (Miller et al., 2008). The average delay between parents first seeking help and the point of diagnosis is quite substantial: in the case of autism spectrum disorder (ASD), for example, parents can expect to wait between 3.4 and 5 years for diagnosis (Crane et al., 2016).

The role of parents in early intervention is critical because they can heavily influence their child's development (Macvarish et al., 2014), especially if they are actively involved in intervention strategies and techniques. However, the additional demands of raising a child with special educational needs can exacerbate stress (Crane et al., 2016), and this stress is often associated with the effort to maintain partnerships through 'battles' with professionals (Ryan & Quinlan, 2018). Parents often have to divert their time and resources away from their child to navigate complex health and education services, such as understanding different referral systems. These additional responsibilities reduce the parent's capacity to have a positive influence on their child and to become the leading interventionist (Home et al., 2015), especially when the increase in expectations becomes unmanageable.

Self-efficacy (Guimond et al., 2008) is considered a key component of adequate parenting. It is defined as 'beliefs or judgements about one's ability to be successful in the role of a parent' (Hess et al., 2004). According to Coleman and Karraker (1997), if a parent feels knowledgeable and confident in their role, they will experience increased levels of PSE, and this will impact positively on their competency (Sanders, 2003). Healthy levels of PSE are also thought to act as a buffer to parenting stress (Raikes & Thompson, 2005), enabling challenges and adversity to be managed more effectively (Gelbar et al., 2014). PSE levels have also been found to be a predictor of a child's psychosocial and educational outcomes (Ardelt & Eccles, 2001); for example, children are better able to self-regulate when a parent has good levels of PSE (Purdie et al., 2004). Parents with low PSE, however, are at risk of frustration, stress and depression (Sanders & Woolley, 2005). Coleman and Karraker (1997) outline primary methods for developing PSE, which can impact both positively and negatively. First, vicarious experiences describe how parents initially learn through observation of others and then reflect on their own experiences to develop a working model for their parenting. According to attachment theorists, this working model will be dependent on the parent's attachment style and how they develop trust. For example, a parent who consistently had their own needs met in childhood, thus developing trust in others, will also seek to cultivate this in their parenting style (Kohlhoff & Barnett, 2013). Next, parents rely on verbal persuasion, in which they receive feedback and support from trusted others, whether this be from friends, family or professionals. Providing feedback during task-specific early intervention experiences is beneficial for parents' PSE (Guimond et al., 2008). The parent will also experience physiological/emotional arousal in which their current emotional state informs their self-efficacy. Where this is positive, such as when their child meets a developmental milestone, the parent is likely to continue to face new experiences or challenges without unnecessary stress. However, frequent negative affective states can elevate stress and create avoidance issues as the parent becomes fearful of disappointment or failure (Benedetto & Ingrassia, 2017). Daily interactions with their child cultivate the competence and PSE of the parent. When a child makes progress in their development, PSE has the potential to increase, but it is also essential to consider how PSE is affected when a child's development does not follow the typical milestones. Therefore, the parent may have to reframe their thinking from a traditional view to a more personalised and adaptive view that more aptly describes their child's particular developmental differences. When this occurs, Allred and Hancock (2012) describe a process known as 'positive adaptation' in which the parent ascribes meaning to the developmental differences.

At the start of early intervention, it is unlikely that a parent will fully know or understand the nature of their child's special educational needs and/or disabilities. The diagnostic process is considered to cause significant emotional stress to parents (Graungaard & Skov, 2007) and could therefore impact on PSE. Despite there being a wealth of research on self-efficacy, including specific studies on PSE and diagnosed developmental delays, such as ASD (Hohlfeld et al., 2018), there is limited research on the diagnostic process and PSE. This study intends to address this gap in knowledge and examine how PSE is impacted when parents experience waiting lists in early intervention.

Methodology

Design

Quantitative data were collected using a correlational design, in which the Early Intervention Parental Self-Efficacy Scale (EIPSES) (Guimond et al., 2008) provided an overall PSE score. Waiting times were also recorded.

Qualitative data were collected via semi-structured interviews. The interview data were transcribed verbatim using the Jefferson (2004) model in preparation for Thematic Analysis (Braun & Clarke, 2006).

Measures

The EIPSES, which has been tested for reliability and validity (Guimond et al., 2008) was administered using Qualtrics. The survey intended to measure (a) the degree to which caregivers perceive themselves as being personally competent and capable in parenting their child and (b) the extent to which they believe their child's outcomes to be a function of environmental influences or constraints. The survey produces an overall PSE score and has two additional factors: (1) parent outcome expectations (POE), and (2) parent competence (PC), which can be scored separately.

The survey comprises a 16-item 7-point Likert scale with responses ranging from strongly disagree (1) to strongly agree (7). Scoring for items 3, 5, 6, 8, 12, 16, 17, 19 and 20 were reversed so that for all items, higher scores reflected greater perceived self-efficacy.

A semi-structured interview was designed using previous findings in ASD research which addressed the experiences of parents during early intervention (Crane et al., 2016). Participants shared their age, their ethnicity, and the length of time they had waited for early intervention. The interview had five sections: demographic details, experiences of early intervention, quality of support, interactions with professionals, and perceived PSE.

Participants

Mothers were recruited for both phases of the research because prior studies suggest that it is mothers who often take on the majority of caregiving roles and are often subject to increased caregiver stressors (Sharma et al., 2016).

Participants for the quantitative phase of the study were 197 mothers aged 18 to 55 years (see Table 1). Participants described themselves as white/white British (88.8%), black/black British (2.5%), Asian (3.5%), mixed/multiple ethnicity (4.6%) and other (0.5%).

Qualitative participants

Participants were six mothers ($N = 6$) with a mean age of 38 ($M = 38.16$, $SD = 5.19$) who described themselves as white/white British (100%). In adhering to the sequential explanatory design, participants were informed via social media that there was a second phase of data collection through semi-structured interviews and they were able to participate on a voluntary basis. A recruitment advert was shared on Facebook, Instagram and Twitter. The advert included a description of the study, informed consent procedures, the right to withdraw, and the right to confidentiality and privacy. Participants were given the choice of a face-to-face interview or via video-conferencing using Skype software. The majority of participants chose the latter option as this suited their circumstances.

Table 1: Age ranges of participants

		Frequency	%	Valid %	Cumulative %
Valid	18–24 years	3	1.5	1.5	1.5
	25–34 years	46	23.4	23.4	24.9
	35–44 years	99	50.3	50.3	75.1
	45–54 years	42	21.3	21.3	96.4
	55–64 years	7	3.6	3.6	100.0
	Total	197	100.0	100.0	

For thematic analysis, the sample size is dependent on the subjective knowledge of the researcher who needed to ensure that the number chosen was 'small enough to manage the material and large enough to provide a new and richly textured understanding of experience' (Fugard & Potts, 2015). Between six and 10 interviews were estimated to be enough to generate a valid dataset (Braun & Clarke, 2006). Saturation, where 'mounting instance of the same codes, but no new ones are generated' (Given, 2015), occurred by interview six, and therefore no further interviews were carried out.

Quantitative results

Sample characteristics

The Shapiro-Wilk test ($p \geq 0.05$) (Razali & Wah, 2011; Shapiro & Wilk, 1965) and a visual inspection of their histograms, normal Q-Q plots and box plots showed that PSE scores were approximately normally distributed for each waiting time interval. Skewness and kurtosis remained within the expected range. Pearson's correlation coefficient was chosen to analyse the data, which included analysis of the overall PSE score and the additional factors of (a) parent outcome expectations (POE) and (b) parent competence (PC).

The mean overall score of the EIPSES was calculated ($M = 4.60$, $SD = 0.54$) along with the two additional factors: parent outcome expectations ($M = 4.34$, $SD = 0.67$) and parent competence ($M = 4.34$, $SD = 0.83$).

Pearson's correlation

The overall PSE mean score (PSEMean) was analysed using a two-tailed Pearson correlation test. There was a very weak positive relationship between the length of waiting time and self-reported PSE, but this was not statistically significant; r (195) = 0.012, $p = 0.873$. These results show that time spent on waiting lists for early intervention do not correlate with reduced parental self-efficacy.

In addition, the mean score for the two additional survey factors were also analysed with the Pearson correlation; these were parental outcome expectations (POEMean) and parental competency (PCMean). There was no statistically significant relationship between the length of waiting time and POEMean; r (195) = 0.080, $p = 0.262$. These results show that the length of time spent on waiting lists does not alter the expected outcomes a parent may have for their child's early intervention.

There was a very weak negative relationship between length of waiting time and PCMean but this was not statistically significant; r (195) =

−0.042, $p = 0.554$. The results show that the length of time spent on a waiting list does not impact on the competence levels a parent has during early intervention.

Qualitative results

Once the quantitative stage was analysed, semi-structured interviews were completed to gather a more in-depth perspective of PSE. The data were recorded, uploaded to a secure university account and manually transcribed verbatim. The recordings were listened to several times to ensure accuracy. Using the Braun and Clarke (2006) method, in the first phase, initial thoughts and ideas were noted down at the end of each interview and the lead researcher became familiar with the dataset, while observing for saturation. Early on in the interview process, it became clear that there were strong potential themes and subthemes. The transcribed data were read and re-read multiple times and these 'repeated readings' (Braun & Clarke, 2006) allowed the researcher to become immersed in the data. The second phase looked at the frequency of the identified patterns and refined them to a set of codes that were pertinent to the research question. The third phase involved the search for patterns and subthemes and the codes being allocated to broader themes. Thematic maps were used to ensure that codes accurately represented the themes and provided a clear link to the research question. Themes were discarded if there was insufficient supporting evidence or if the data were unclear, thus placing the data at risk of being misinterpreted. Once a coherent pattern was formed, phase four was used to review and organise the themes in order of prevalence. This led to the removal and exclusion of any themes that did not fit with the dataset or answer the research question. Phase five included the defining and naming of themes and subthemes, and specific data were chosen which would provide evidence of the theme; for example, specific quotations. The themes were then written up in a coherent order for phase six (Table 2).

Early intervention timeframes: 'wait and see' mentality

All participants understood that long waiting lists were to be expected in early intervention, and did not necessarily view this as a problem because, as one participant put it, *'at least you know you are on the ladder to getting support'* (participant 6). Participants became more frustrated in scenarios where the initial referral was rejected, thus not even making it onto a waiting list. The recommended timeframe for early intervention is up to five years of age (Bate, 2019) but five out of six participants were sent away and told to *'wait and see'* (participant 2) when they raised concerns

Table 2: Thematic analysis themes and subthemes

Theme	Subthemes
1. Early intervention time frames	1.1 ‘Wait and see’ mentality
2. Interactions with professionals	2.1 Being listened to
	2.2 Sharing the worst days
	2.3 Feedback
3. Personalisation	3.1 Lack of differentiation
4. Parents as partners	4.1 Battles and conflict
	4.2 Information
5. Advocacy	5.1 Self-efficacy
	5.2 Parent advocacy

suggesting that their voices were not being heard. Participants shared experiences of being told that boys and girls develop at different rates and that their children would grow out of their delays. Despite the parents sharing concerns, if the professionals were not in agreement, the participants felt they needed to *‘jump through hoops’* (participant 6), *‘go through the motions’* (participant 1) and *‘tick boxes’* (participant 4) to access help, and this led to periods of self-doubt. Participants began to second-guess their judgements, and in some cases children were discharged from services prematurely, which resulted in a high number of re-referrals. Participants felt rushed through early intervention experiences and found that they had very little time to convey important information about their child, which led to a general misunderstanding of needs; for example, *‘the appointments have been extremely short, and we have to wait at least six months every time we want to see someone’* (participant 3). Therefore, interactions with professionals became a key theme in how self-efficacy was maintained throughout early intervention.

Interactions with professionals: being listened to

Participants noted that interactions with professionals could become quite fragile and adversarial. They understood that professionals were facing mounting pressure with funding cuts (participant 2) but in some cases, there appeared to be a lack of competency and skill in parent partnership: *‘There is just no listening … there is listening as in they will stop and listen, but they will not hear’* (participant 1). This concept of not being heard came up several times, and participants felt that professionals contributed negatively to their experiences by *‘fobbing’* them off (participant 4). Participants felt invisible in discussions between professionals, and in one example, a parent attended a meeting with a teacher and specialist and was not supported to contribute her thoughts or be involved in decision-making (participant 4, participant 2). Participants often felt conflicted in the presence of professionals whom they felt very rarely harnessed their knowledge about their children. One participant said: *'just because I am not a professional… doesn't mean I should be discounted because I know my son better than any of the professionals'* (participant 3). Interestingly, participants found that they had little opportunity to fully explore all aspects of their child's special educational needs and/or disabilities, which negatively impacted on their mindset.

Interactions with professionals: 'worst days'

One participant described how she continually had to share her child's *'worst days'* (participant 1) to ensure her concerns were taken seriously. This impacted on her mental health because she continually had to think negatively about her child and this felt *'in itself is a depressing life to live'* (participant 1). This was mirrored by another participant who stated: *'No one asks me about the good things, I am constantly talking about my child in her worst-case scenarios'* (participant 6). The participants stated that the increased negativity added to feelings of anxiety and sadness, and there was concern that professionals generally had low expectations of their children. For example, one specialist's response to a parent questioning the negative language on a developmental report was *'Well, what did you expect?'* (participant 2). In another situation, a participant shared how professional boundaries were crossed when a specialist asked sensitive and invasive questions in front of the child, including whether there was abuse in the marriage (participant 5). Participants had an understanding that the professionals were there to facilitate support through early intervention, and that information sharing should have scaffolded high-quality early intervention.

Interactions with professionals: feedback

The participants acknowledged and agreed that it made sense for them to be their child's main early interventionist with the professional's facilitation. However, they believed this was difficult to achieve because they rarely had a named professional providing support and feedback was not consistently given (participant 2). The participants did not like the feeling of isolation and not knowing if they were doing the right things; one participant said: *'you realise you have to make sense of all this by yourself'* (participant 1). Participants suggested that it would make more sense to have a named contact or someone you could access for *'light touch'* support. For example, one participant used Skype sessions privately, while another provided videos to receive feedback:

> *'I just need to know I am not alone, I do not need heavy input, but to be able to send a video or even text or photo and for someone to say, "This is great, try this next".'* (participant 6)

Personalisation: lack of differentiation

Participants found that a *'one size fits all'* (participant 1) approach created issues within early intervention and resulted in mismatched support. In one instance, a participant went along to parent-mediated therapy with older children who had very different needs to her own child. The lack of personalisation made it difficult for parents to implement strategies, and the lack of differentiation meant that support often sat at the *'surface level'* (participant 2). It was not uncommon for participants to find themselves in therapy groups with children with varying and very different needs. One participant described her frustration at figuring out how to implement *'abstract strategies'* (participant 1).

All participants explained that they felt frustrated that professionals did not get to know their children, and appointments were often in clinical and unfamiliar settings. In one situation, an assessment took place in a building that had bars on the windows. The specialist was dressed in a suit with a clipboard and rarely interacted with or got to know the child (participant 5). The participants suggested that assessments and therapy should take place in spaces that felt safe and welcoming to both the parent and the child (participant 5; participant 1).

Parents as partners: battles and the impact of conflict

Across the six interviews, there were remarkable similarities in the participants' descriptions, mainly that their experiences had all been a *'battle'* (participant 5) for support. One participant explained: *'I wake up in the morning and often think, which professional am I going to be arguing with today?'* (participant 6) and another said that she had more conflicts and challenges than she had ever experienced before (participant 2). All participants stated that they had lost trust in the professionals as advocates for their children and found that the child's best interests were often overlooked (participant 1). They believed that an equal partnership needed to re-established through shared decision-making and more useful information sharing.

Parents as partners: information sharing

All participants said that they had been given very minimal information or signposting to support their child, and in most cases, the advice focused on basic parenting skills as opposed to specific strategies. They found this *'belittling'* (participant 1), *'patronising'* (participant 6) and *'tokenistic'* (participant 1), and did not feel equipped with the tools to succeed. They emphasised that they trusted information given to them by professionals, but when this was not provided, they had to seek out information independently and could not be sure of its reliability. This added an additional burden to the participants' parenting workload, and *'time and energy could be used so much more effectively if professionals would give information and advice that could actually be used'* (participant 3).

Advocacy: self-efficacy

PSE was a dominant theme throughout the interviews and participants shared that they had to be very intentional in maintaining their self-belief; as one participant put it, *'You have to have a lot of faith in yourself to go and argue with professionals who are saying there is nothing wrong'* (participant 4). The participants believed that professionals posed a threat to self-efficacy and that doubt could creep in if unchecked. The idea that they had to fight for support left participants feeling confused and made them second-guess whether their concerns were warranted (participant 1). To eliminate this threat to self-efficacy, participants felt that professionals needed to understand their roles as advocates.

Professional advocacy

Participants did not believe that professionals were advocates for their children because they often made decisions and judgements that limited their access to support. The idea that the professional *'knows best'* created disequilibrium (participant 3) in the partnership and made participants doubt themselves. Participants felt that professionals should begin to take parents more seriously and work alongside rather than against them; otherwise, the situation becomes non-conducive to the child's progress (participant 6).

Discussion

This study found that there was no significant relationship between the length of time spent on a waiting list and perceived PSE. Unexpectedly, interviews indicated that securing a space on the waiting list gave weight to the parent's self-efficacy because it confirmed the validity of their concerns about their child's development.

Prior research in early intervention reinforces the idea that professionals should work in close partnership with parents, ensuring that trust and collaboration lead to the effective identification of needs (Hodkinson, 2015). However, research also suggests that partnerships between professionals and parents remain contentious and burdened by conflict (Ryan & Quinlan, 2018). These findings imply that there has been a failure on the professionals' part to collaborate with the parents. The professionals' lack of belief in parents' knowledge of their children could potentially transfer into a lack of belief that parents have about themselves. This highlights the importance of professionals trusting in the judgements that parents make about their children and developing more co-operative behaviours in the initial stages of early intervention (Brotherson et al., 2010).

Building strong foundations in partnerships has the potential to provide benefits for the child and family and would reduce the longer-term burden on services as parents become more empowered and less stressed (Barlow et al., 2002). Being equipped with information has also been identified as a source of empowerment for parents (Alsem et al., 2017), but often the participants were sent away with minimal guidance on how best to meet their child's needs. Given that the acquisition of information can be a coping strategy for parents, this study identifies an 'information gap' which, if addressed, could alleviate the stress and anxiety that is associated with the additional responsibilities of raising a child with special educational needs and/or disabilities (Crane et al., 2016). Research has already found that 'homework' is a positive indicator for engagement and treatment satisfaction (Danko et al., 2016), and it is important to use this knowledge to inform the way in which early intervention services are organised. For information to be empowering, parents also need to have a sense of ownership and they need to understand what purpose the information serves. If parents are expected to be the lead interventionist, they should be equipped with the relevant knowledge, tools and techniques to become successful in this role, and they should have an opportunity to monitor their progress and receive feedback.

PSE has been found to be maintained in part through feedback (Benedetto & Ingrassia, 2017), particularly if parents are required to complete early intervention-specific tasks. While the participants agreed that they were best placed to be the lead interventionist (Stokes et al., 2016), they felt that feedback would help them to continue with intervention while they waited for professional support. Providing 'light touch' contact during waiting periods could be beneficial for the maintenance of PSE, because although parents may use other sources to access information, such as social media support groups, research suggests that speaking with a health professional remains a strong preference (Domínguez & Sapiña, 2015). Participants rarely felt that professionals equipped them with the skills and knowledge to continue intervention at home (Siller & Sigman, 2008) because of a lack of personalisation. The emotional state of a parent can affect PSE, which has been found to be difficult to maintain when raising a child with special educational needs or disability (Guimond et al., 2008). Current research indicates that services are under immense pressure amidst austerity measures (Longfield, 2019), and it is important to acknowledge that the experiences parents have with individual professionals are often indicative of wider organisational challenges.

There appeared to be a lack of shared decision-making and the perspectives of parents were often overlooked in favour of the view that the 'professional knows best', which contradicts the principles of parent-mediated early intervention. In order to secure support and to continue in their advocacy, the parent is required to think frequently about their child on their 'worst days' which negatively impacted on the parent's mental health, but equally became a driver for their continued advocacy. There is little research that examines the long-term impact of deficit thinking on PSE, but it could prove essential in understanding how parents sustain self-efficacy and advocacy over time.

It was clear from this study that the combined features of PSE, advocacy and competency play a crucial role in early intervention. The degree to which these features inform the design and delivery of health and education services is not fully understood, so further research should seek to understand how services can better utilise these psychological aspects of parenting to improve the effectiveness of the support they offer to families.

Conclusion

The research aimed to establish (a) whether there was a relationship between length of time on waiting lists and PSE, and (b) whether there were specific themes or patterns associated with delayed early intervention and PSE. While the study found that there was no relationship between waiting lists and PSE, the poor quality of early intervention experiences was found to impact negatively on self-efficacy. It is essential that early intervention services move beyond the 'professional knows best' mentality that so often leads to poor-quality partnerships. By acknowledging the importance of the parent's voice in decision-making and service design, early intervention will be closer to achieving its purpose of reducing poor long-term outcomes and additional burdens to public services. Early intervention is a challenging experience, and for it to be useful for parents, they must feel empowered in maintaining their self-belief.

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Address for correspondence:
Dr Emily Harrison
Faculty of Business, Law and Social Sciences
Birmingham City University
Curzon Building
City Centre Campus
4 Cardigan Street
Birmingham B4 7BD
UK
Email: Emily.harrison@bcu.ac.uk

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