

Stresses, challenges, and rewards of home-based applied behaviour analysis intervention for children with autism spectrum disorder

Vikki Parker¹
Carrie Childs¹

¹ *University of Derby, College of Life and Natural Sciences, Derby*

Corresponding author: Dr Carrie Childs, College of Life and Natural Sciences, University of Derby, Kedleston Road, Derby, DE22 1GB, United Kingdom. Tel: +44 (0)1332 59428. Email: c.childs@derby.ac.uk

Abstract

This study examined the experiences of five parents who had children with autism spectrum disorder, who were receiving applied behaviour analysis-based intervention in their home setting, in order to better understand the rewards and challenges associated with such a program. The limitations and difficulties of home-based programs for children with autism spectrum disorder have been well documented. These include the impact on family wellbeing, difficulties recruiting program tutors, and problems obtaining funding from local education authorities. Semi-structured interviews were conducted and data analysed using interpretative phenomenological analysis. Three themes emerged: (i) absence of personal space: “one of the most difficult and least exciting things of running a home-program is the fact that it’s your home”; (ii) having personal agency: “the ability to sustain the program and fight the system”; and (iii) feeling empowered: “anyone can learn anything”. Findings highlighted the prevalence of problems caused by “the system”. Difficulties of implementing an intervention within the home and financial strain were additional stressors. It was concluded that challenges with applied behaviour analysis-based intervention are distinct from the intervention itself. Nevertheless, parents felt supported by their intervention teams. The results of this study are discussed in relation to current applied behaviour analysis-based intervention provisions.

Keywords: *applied behaviour analysis; autism spectrum disorder; qualitative; interpretative phenomenological analysis*

This article explores parents’ experiences of applied behaviour analysis-based intervention for their children with autism spectrum disorder. Along with a number of other interventions, such as the early start Denver model, which applies procedures that are based on the principles of applied behaviour analysis (see Waddington, van der Meer, & Sigafos, 2016) and parent-mediated social communication therapy (see Pickles et al., 2016), applied behaviour analysis is a scientifically validated approach. Research has suggested that applied behaviour analysis-based interventions have yielded positive outcomes (e.g. Remington et al., 2007). However, many professionals do not have specific applied behaviour analysis training, and many parents set up home-based provision. The difficulties of home implementation are well documented. Grindle, Kovshoff, Hastings, and Remington (2009) noted that 30% of parents reported their child having fewer opportunities to socialise. Many parents have felt that they had no choice in the matter of home provision (Batten, Corbett, Rosenblatt, Withers, & Yuille, 2006), and that their voices have been unacknowledged and misunderstood by professionals (Mueller & Buckley, 2014).

Other challenges include the impact on family wellbeing. This is important as parents of children with autism spectrum disorder suffer greater levels of stress and depression than parents of children with other developmental disabilities (Estes et al., 2009). Schwichtenberg and Poehlmann (2007) found that mothers of children participating in home-based applied behaviour analysis-based programs experience similar depressive symptoms as mothers in other autism spectrum disorder samples. Mothers also reported fewer depressive symptoms when their child was engaged in more intervention hours per week. This suggests that home-based intervention provision itself may not cause stress and depression and that a more intense program may be beneficial. However, less intensive intervention is sometimes opted for, which Cater et al., (2011) suggested could reflect the high cost of programs in Australia, particularly when no government funding is available. Mothers who are involved in their child's program may experience greater levels of personal strain. This suggests that intense programs that do not rely heavily on parents as therapists or as program coordinators are optimal. Placing high demands on family resources may undermine intervention effectiveness.

Grindle et al., (2009) explored parents' experiences with early intensive behavioural intervention. They found many benefits of a home-based program, for example tutors provided additional support in the home. However, difficulties included finding and recruiting appropriate candidates. Parents in this United Kingdom sample had also experienced problems obtaining funding from their local education authorities, with some resorting to measures such as re-mortgaging their homes to self-fund the program. Nevertheless, McPhilemy and Dilenburger (2013) reported high levels of parental satisfaction with applied behaviour analysis-based intervention. This research has highlighted some of the most rewarding and the most challenging aspects of an intensive home-based early intervention program. However, parental expectations, impact, and challenges as outcome measures, captured using Likert scales, have provided limited insight into the quality of experience of applied behaviour analysis-based intervention and the importance of this for program implementation. Furthermore, there has been limited emphasis on the importance that parents place on aspects of applied behaviour analysis-based interventions and their understanding of the scientific underpinnings upon which interventions are derived (Carlson, Carter & Stephenson, 2015). A shift to parents as experts of their own experience is necessary. The experience of parenting a child with autism spectrum disorder results in changes to parents' sense of self (Cashin, 2004). The "taken-for-grantedness" of their world shifts, including expectations of normality for the child (Grindle et al., 2009).

The present study aimed to extend previous research on parent's experiences of applied behaviour analysis-based intervention by facilitating an understanding of the challenges and rewards of running a home-based program. The objective was to be of benefit to parents, professionals, applied behaviour analysis-based intervention tutors, and policy makers by enhancing understanding of parents' experiences, to better support them in the future.

Method

Participants

Participants were recruited via advertisements on an autism spectrum disorder charity webpage and in a variety of relevant social media groups. The sample of five United Kingdom based participants was purposive. All participants had at least one child with an autism spectrum disorder diagnosis who received applied behaviour analysis-based intervention at or before the age of 5 years. All programs had been running for at least 12

months in the home setting, with a minimum of 20 hours of intervention time per week. Data were collected in accordance with the British Psychological Society's Code of Human Research Ethics (2018).

Setting

Interviews were conducted using Skype video call software and via telephone. The interviewer conducted all interviews from a quiet office. Participants were asked to ensure a minimised level of distraction during the interview.

Procedures

Data were collected using semi-structured interviews, which allowed the researcher to direct similar questions to all participants, while leaving room for participants to introduce additional areas (Smith et al., 2009). Data were analysed using interpretative phenomenological analysis.

Data analysis

The focus of interpretive phenomenological analysis is individuals' lived-experience of particular phenomena (Smith, Flowers, & Larkin, 2009). Interpretive phenomenological analysis is an ideographic mode of enquiry, which is not concerned with findings that are generalisable across settings. However, this research aspired to logical generalisations that may be of interest to professionals in related fields (Smith, 2008). The analysis was carried out following Smith et al.'s (2009) guidelines. This involved: (i) *reading and re-reading* the transcripts while listening to the audio files in order to enter the participants' world; (ii) *initial noting* of exploratory comments; (iii) *developing emergent themes* for each participant with themes that reflect both the participants' unique accounts of home implemented applied behaviour analysis-based intervention as well as the analysts' interpretation; (iv) *searching for connections across emergent themes* and mapping how themes fit together; (v) *moving to the next case* and repeating steps 1 to 4 for each transcript, which must be viewed individually, bracketing off the ideas that emerged from the analysis of previous transcripts. Only one transcript was analysed each day, to facilitate this; and (vi) *looking for patterns across cases* and comparing each case to find commonalities. This involved re-grouping and re-labelling themes as convergences manifested across themes.

Findings

Three major themes emerged from the interpretive phenomenological analysis: (i) absence of personal space: "one of the most difficult and least exciting things of running a home-program is the fact that it's your home"; (ii) having personal agency: "the ability to sustain the program and fight the system"; and (iii) feeling empowered: "anyone can learn anything."

Absence of personal space

"One of the most difficult and least exciting things of running a home-program is the fact that it's your home"

This theme captures the experiences of running an intervention in the home setting. Kath¹ described the intensity of the program:

¹ Names of participants have been changed to preserve anonymity.

probably one of the most difficult and least exciting things of running a home program is the fact that it's your home ... at some stages we were running the program 70 hours plus, so that's like 10 hours a day, 7 days a week. You can imagine, you know, I had a team of between 10 and 12 people coming in and out; it was like Piccadilly Circus here. (Kath)

Kath described a busy household, emphasising the effort needed "10 hours a day, 7 days a week". Kath suggested that this did not feel like a normal home environment, metaphorically likening it to "Piccadilly Circus". She later described how "some days you don't feel like having people coming in and out of your house but they're there anyway", highlighting that her choice was restricted.

Many participants identified struggles with time constraints that result in personal sacrifice;

The time constraints of having to be around a lot because your child isn't off sort-of 9 [am] to 3 [pm] and conventional schooling and you know you haven't got that block of time to be doing something, or working. You know, I had a career before this which was very much, gone on hold. You know it is impossible to work and develop myself and have my own life outside of the program. But it's the time constraints I find the trickiest... (Kath)

Kath emphasised that it was "impossible" for her to "work and develop" herself, depicting personal strain. This extract demonstrated Kath's sacrifices, constructing her life around the program. Other participants also referred to "time constraints". For some parents, a less intense program may have better "fitted together" with wider family needs. Hannah described her experience with fewer hours of intervention:

I can also go and collect Harry's big sister from school and it just means that I get an hour with her and we go and have a coffee or whatever. And then we come home and Harry's session finishes and then it's tea time and it all just kind-of, it all just kind-of fits together ... and also just a bit of a break to be honest. (Hannah)

The program allowed Hannah to spend time with her second child. Just having "an hour" with Harry's sister or "half an hour" to herself was an important aspect that she valued as it allowed her a "break."

Some participants described difficulties with being at home to hear their child during their session:

It just felt like we lived in a zoo for so long and I was just like my nerves got wrecked, I just couldn't stand all that noise. I just wanted the silence and you know the house isn't big enough so wherever they are I can hear them screaming even though I close the doors. And that's actually not very fortunate that you're basically hiding in your own house, you just kind-of want to live a normal life but you cannot. (Mark)

Mark likened his house to a “zoo”, where he felt trapped and unable to escape the noise. Emphasising that it was his “own home” suggested a feeling of loss of control. Being at home was overwhelming; “my nerves got wrecked”.

Having personal agency

The ability to sustain the program and fight the system

This theme captures the impact of sustaining a program and incorporates experiences of potential barriers. When asked to describe the most difficult aspect of his experience Jason replied:

The biggest challenge for us, to be honest, hasn't been the program itself. It has been the ability to sustain the program and fight the system with a capital “S”, that was unwilling to do anything for us and I think that that was a real challenge for most families you come across in this country. (Jason)

Jason described the “system” as unsupportive, an entity that must be fought. He noted that they were “unwilling to do anything for us”, and suggested that this was a significant problem across “this country.” This suggested that it is “the system”, rather than “the program itself” that was an issue, echoing Australian research (Carter et al., 2011), where there was a lack of government funding to support interventions. Maria described her experience of her sons' tribunals in a similar manner:

Last year when they refused to put ABA [applied behavioural analysis] [referring to SEN (special educational needs) statement] I appealed and I took council to the SEN tribunals. We had two days, one for one boy, same for second boy, June last year and it was terrible. I mean the amount of preparation me and the whole ABA team and consultant put into that. The amount of money I had to spend on paying private psychologists, speech and language reports. Having the SEN advocate and all of that for two children and two tribunal days as witnesses that was just unbelievable we had over 1,000 pages of evidence for each boy... it was just unbelievable. (Maria)

Maria described her experience as “just unbelievable” and something that had had a profound impact on her resources; “preparation” (requiring time) and “money”. The pressure on her was doubled because she had twins, and requiring additional significant preparation. The family lost the tribunal for one of her sons and she attributed this to “luck, who you're gonna get in that panel”. At the time of the interview Hannah was in the process of negotiating a school setting for Harry and explained that she was “preparing for the next battle”:

And when I say battle, I guess I mean that if the school won't accept it then we'll have to kind-of re-think the school setting that we're able to send him to, as in one that will accept ABA. (Hannah)

Hannah described anxious anticipation metaphorically depicting the forthcoming “battle”. The term “battle” suggests war, something over which one has little control. The use of the words “accept” and “able” suggest feelings of powerlessness. Hannah continued:

But at the moment we don’t know, we should find out next week hopefully. So I think that’s why I’m kind-of slightly emotional at the moment. (Hannah)

Having been tearful at the beginning of her interview, Hannah attributed her emotion to her anxiety of waiting. Use of the terms “we should” and “hopefully” demonstrate uncertainty that she will receive the answers next week as expected, suggesting an element of distrust.

Feeling empowered

“Anyone can learn anything”

This theme encapsulates parents’ views of applied behavioural analysis; their understanding of intervention efficacy, experiences with professionals, and feelings toward their child’s progress.

Their self-help skills are so much better because of the ABA, like, you know we have children now who are toilet trained who know how to dress and undress themselves, who are, you know, eating nicely on their own and eating a variety of foods ... we can walk miles with them, we can go on public transport, we can go to restaurants, we can go to friends’ places. So all these things used to be very difficult and because of ABA they are kind-of normal now and we can do all these things and family outings and whatever with them now, nicely. So I know that this wouldn’t be possible for them without going through ABA program. (Maria)

Maria’s use of the phrases “the way they just,” and “the stuff they can do now”, emphasise her sons’ achievements. She described one achievement after the other, to reflect her pride and a greater sense of normality; “because of ABA they are kind-of normal now”. She suggested that her sons’ progress would not have been possible “without going through ABA program”. Similarly Kath explained;

It’s been quite remarkable, he’s now just very interactive very chatty, I’d say he’s almost a bit of a nag bag now which is [laughing] ... when he’s nagging on at me I say “Oh my God, Jacob, you know, just to think the specialist said you’d never talk! (Kath)

Kath used humour to emphasise her delight with Jacob’s “remarkable” achievements, demonstrating pride by emphasising what Jacob can do. Kath conveyed a sense of achievement, as Jacob had been able to achieve targets despite professional predictions; “Oh my God, Jacob, you know, just to think the specialist said you’d never talk!” Kath subsequently explained how her experience has empowered her:

We’ve had to break tasks down to such small components to teach him but it just proves if you look at, functionally look at something that

needs to be taught or something a person wants to learn and you get a good enough teaching procedure, anyone can learn anything. (Kath)

The phrase “anyone can learn anything” depicts trust in the efficacy of applied behaviour analysis-based intervention and Kath’s use of the phrase “it just proves” demonstrates confidence in the approach. The words “functionally,” “breaking down”, and “good enough teaching procedure” suggest understanding of scientific underpinnings driving the intervention. Similarly, Jason experienced a shift in focus toward a positive future. Jason described his new found ability to “reach” his son:

You know, if I referred to a neuro-typical five-and-a-half year old, of course they’re a lot more creative in their styles and a lot less prescriptive in how they play with things, yes. But does he independently come up with new things? Yes. Is he able to switch from activity to activity now? Yes. And you know, this, this boy would never be able to achieve...” (Jason)

Jason used rhetorical questions and took pleasure in answering these. He placed great value on what Sammy had learned; “independently” coming up with “new things.” The term “this boy,” accentuates Sammy’s transformation; he “would never be able to achieve” before but now he could. Similarly to Maria, Jason suggested that without applied behavioural analysis-based intervention Sammy would not have achieved these things. Jason too, described his appreciation;

The analogy I would use is that we were banging our head against the door on some of these areas and someone just came around and said “look here is a key, the lock is very rusty and we need to put a lot of oil in it to turn the key round to open the door”. But that’s exactly what we need to do and that’s what ABA did for us. (Jason)

Jason described his personal transformation from the beginning stages; “we were banging our head against the door,” to now. The “rusty lock” depicts the struggles they faced, the “oil” the support he received to overcome those struggles, and the “door” as the barrier between himself and Sammy. The “key,” applied behaviour analysis-based intervention, enabled him to reach Sammy. Jason drew a close to his interview by speaking out to other parents:

I’d highly recommend it to anyone who has a child with autistic spectrum disorder, but I wouldn’t say that if I didn’t think it works and y’know it doesn’t cure our children, it’s not a cure. Our children will stay who they are, they will always have the challenges they have. What this gives them, and what it gives us as parents, is the tools to work round those challenges... (Jason)

Jason reiterated that applied behaviour analysis-based intervention is “not a cure,” which is reinforced by “our children will stay who they are.” Jason used the metaphor “tools” to depict applied behaviour analysis-based intervention as providing the means to “work round” challenges. The metaphor demonstrates the psychological impact of applied behaviour

analysis-based intervention empowering Jason, who is now able to utilise what he has learned.

As a whole, parents clearly demonstrated investments in the intervention. All parents in this study reported feeling satisfied and supported the approach. This confidence in applied behaviour analysis-based intervention is significant as belief in the efficacy of intervention can result in greater optimism.

Discussion

The study provided insight into parents' lived-experiences of applied behaviour analysis-based intervention for their children with autism spectrum disorder. Although participants had unique experiences, similarities between accounts arose, such as feeling a lack of control regarding "the system," and financial strain. Parents reported "feeling empowered" suggesting a sense of a "remarkable" impact of applied behaviour analysis-based intervention on their children.

An important finding is that many of the difficulties reported by parents were secondary to the intervention itself, such as problems with "the system", financial strains and staff presence in the home. These challenges may be difficult to eliminate. As the process model of stress and coping outlines, when faced by impassable stressors, parents may experience elevated levels of stress and difficulty coping each time they reappraise the stressor (Lazarus, 1966 as outlined in Beresford, 1994). In addition, parents' sense of self may shrink through loss of spontaneity, loss of social contact and as a result of having fewer "things" for themselves (Cashin, 2004). As Cashin highlights, extreme personal sacrifices may result in further encroachment of the "self", leading to depersonalisation. Parents in the present study felt similarly restricted by their perceived lack of control, choice and normality, which in some cases lasted for a prolonged length of time. As such, this study highlights that stressors that are secondary to interventions, such as a lack of support from "the system" must be addressed to avoid poor outcomes for both parents and children.

A dominant aspect of parents' experiences was that the intervention can promote positive experiences, such as enabling parents to take their children out on public transport, to restaurants and "friend's places," without incurring as much personal strain. As well as encouraging the child to engage with a range of activities, applied behaviour analysis-based intervention empowered some parents in the present study with greater social contact and spontaneity for themselves. The current study was limited to participants who had a high level of program supervision from one or multiple **board certified behaviour analysts (BCBAs)**. Whether this is an outcome experienced by parents with children engaged in fewer hours of provision is a question for future research. These findings have clear implications for policy and practice as it is improbable that parents, teachers or therapists alone could enable the child with autism spectrum disorder to take-part in a range of meaningful activities. A collaborative approach is needed to support engagement in recreational activities (Potvin, Prelock & Snider, 2008).

According to McPhilemy and Dillenburger (2013) outcomes for the child and their parents is greatly enriched when parents and professionals share the same goals. This is optimally achieved when professionals have an enhanced understanding of parents' perspectives, as an important aspect of support is feeling understood (Featherstone, 1980). This study has given parents a voice and explored their lived-experiences of applied behaviour analysis-based intervention provision, which works towards achieving this outcome. Service providers must understand the basic values of parents in order to maximise the success of an intervention.

For the parents in the present study, applied behaviour analysis-based intervention itself did not negatively impact their experiences and indeed such interventions may empower parents and give them hope. In any case, parents of children with Autism Spectrum Disorder have an increased vulnerability to stress and ill health (Estes et al., 2009). If “the system” exacerbates this issue, providing barriers to intervention and leaving parents distrusting of professional values, it may increase parental health-risks and hinder their ability to cope. Although this study focused on the experiences of a UK sample, it is evident from previous research (e.g. Carter et al., 2011) that issues such as financial strain and lack of government support with applied behaviour analysis-based intervention affect countries across the globe. It is important to encourage dialogue between parents and professionals in a manner that empowers parents and allows them to feel better understood and supported.

References

- Batten, A., Corbett, C., Rosenblatt, M., Withers, L., & Yuille, R. (2006). *Make schools make sense: Autism and education*. Retrieved from <http://www.autism.org.uk/get-involved/campaign-for-change/uk-wide-campaigns/past-campaigns/make-school-make-sense.aspx>
- Beresford, B. A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35(1), 171-209.
- Carlson, S., Carter, M., & Stephenson, J. (2015). Decision-making regarding early intervention by parents of children with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 27(3), 285–305.
- Carter, M. A., Roberts, J. B., Williams, K. C., Evans, D. D., Parmenter, T. E., Silove, N. F., Clark, T. G., & Warren, A. G. (2011). Interventions used with an Australian sample of preschool children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(3), 1033–1041.
- Cashin, A. (2004). Painting the vortex: The existential structure of the experience of parenting a child with autism. *International Forum of Psychoanalysis*, 13(3), 164-174.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13(4), 375-387.
- Featherstone, H. (1980). *A difference in the family: Living with a disabled child*. Middlesex: Penguin.
- Grindle, C. F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents’ experiences of home-based applied behaviour analysis programs for young children with autism. *Journal of Autism and Developmental Disorders*, 39(1), 42-56.
- McPhilemy, C., & Dillenburger, C. (2013). Parents’ experiences of applied behaviour analysis (ABA)-based interventions for children with autistic spectrum disorder. *British Journal of Special Education*, 40(4), 154-161.
- Mueller, T. G., & Buckley, P. C. (2014). Fathers’ experiences with the special education system: The overlooked voice. *Research and Practice for Persons with Severe Disabilities* 39(2), 119-135.
- Potvin, M. C., Prelock, P. A., & Snider, L. (2008). Collaborating to support meaningful participation in recreational activities of children with autism spectrum disorder. *Topics in Language Disorders*, 28(4), 365-374.
- Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., ... & Aldred, C. (2016). Parent-mediated social communication therapy for young children

- with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet*, 388(10059), 2501-2509.
- Remington, B., Hastings, R. P., Kovshoff, H., degli Episona, F., Jahr, E., Brown, T., Alsford, P., Lemaic, M., & Ward, N. (2007). Early intensive behavioral intervention: Outcomes for children with autism and their parents after two years. *American Journal of Mental Retardation*, 112(6), 418-438.
- Schwichtenberg, A., & Poehlmann, J. (2007). Applied behaviour analysis: Does intervention intensity relate to family stressors and maternal well-being? *Journal of Intellectual Disability Research*, 51(8), 598-605.
- Smith, J. A. (2008). *Qualitative psychology: A practical guide to research methods* (1st ed.). London: Sage Publications.
- Smith, J. A, Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Waddington, H., van der Meer, L., & Sigafoos, J. (2016). Effectiveness of the Early Start Denver Model: a systematic review. *Review Journal of Autism and Developmental Disorders*, 3(2), 93-106.