

A Parent's Perspective is Worth a Thousand Words: Parents of Children with ASD and Their Perspectives on a Community-Based Parent Education Program

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Abstract: In 2012, several community-based agencies in the Greater Toronto Region of Ontario overseeing behaviour intervention services for young children with Autism Spectrum Disorder (ASD) began delivering curricula to parents. Session content focused on ASD characteristics, Applied Behaviour Analysis, increasing awareness of available community resources, and active engagement in their child's learning. Using a mixed methods approach, this research project explored parent perspectives on their involvement in these education sessions. Through constant comparison analysis four major and three minor themes emerged. While parent participants confirmed this education program included relevant content and a favourable delivery format, noteworthy gaps were identified. Implications for practice would be applicable to educators interested in providing quality group-based education to parents of young children with ASD.

Keywords: Parents, Autism Spectrum Disorder, Applied Behaviour Analysis, Disability

Introduction

In January 2012, a partnership of agencies located in the Greater Toronto Region of Ontario expanded behaviour intervention services to include parent education and support. The education component of this service was titled *The Parent Education Pathway* and consisted of ten locally-developed, voluntary, group-based education sessions offered across four phases. Sessions were delivered sequentially and covered a range of autism spectrum disorder (ASD)-related subject matter. Session content was structured around four main attributes: *informed*, *aware*, *active*, and *engaged*. These specific terms were included in written material and referred to often by session facilitators. See Table 1 for a description of attributes included in parent education sessions.

Table 1: Definitions of Attributes Included in Parent Education Sessions

Informed: Provide up-to-date, well-researched information specific to ASD, Applied Behaviour Analysis (ABA), and general parenting practices.

Aware: Increase familiarity with other community resources and agencies available to provide service and support to child and family.

Active: Sessions included small, large group activities with ongoing feedback from facilitators.

Engaged: Parents encouraged to individualize activities to increase relevance to personal situations, promoting engagement at home.

Both authors had a personal interest to explore the topic of parent education through an academic, research-focused lens. In the process of researching for a master's thesis, the primary author saw importance in evaluating the content and delivery format of this education program to help determine if parents perceived their involvement as a meaningful practice. The secondary author was involved as an academic advisor.

Recent studies have recommended further investigation on the content of education sessions available to parents prior to their child with ASD beginning intensive service (Matson, Mahan, & LoVullo, 2009; Burrell & Borrego, 2012). This investigation focused on answering the following research question: For parents who have completed core sessions of *The Parent Education Pathway*, did this program assist them to be (more) active, aware, and involved in their child's development? The content of this parent education program focused on *informing* parents about common traits associated with ASD, increasing their *awareness* of Applied Behaviour Analysis and available community resources while enabling them to be *active* and *engaged* in their child's learning.

Literature

ASD is a broad and multifaceted neurodevelopmental disorder. Key characteristics of ASD are impairments in social communication as well as behaviour excesses and deficits (American Psychiatric Association, 2013). Under revised DSM-5 diagnostic criteria individuals receive a severity level (1-3) based on ASD symptoms. These levels typically correspond to the recommended intensity and delivery method of intervention (American Psychiatric Association, 2013).

The relationship between the perception of parents and diagnosed children has changed significantly over time, shifting from historic, pointed blame to a changed understanding of parents' critical membership on treatment teams (Bettelheim, 1967). Receiving a diagnosis of ASD is a life-changing event for parents and families, with unique stressors such as communication deficits, erratic sleep patterns, and challenging behaviour all adding to stress profiles (Norton & Drew, 1994). Recent investigations identified that guilt associated with time spent with diagnosed children over other siblings was an additional factor contributing to parent stress (Pisula, 2011). Myers, Mackintosh, and Goin-Kochel (2009) investigated the stressful experiences of parenting a child with ASD, asking 350 parents: "How has your child in the autism spectrum affected your life and your family's life?" (p. 670). Stress was the most reported theme with 70% of parental responses including this term. Parents used the terms *painful* and *constant* as descriptors for their stress. These findings are consistent with Steiner et al. (2012) who found that parental stress of those caring for children with autism was consistently described as severe across cultural and geographical areas, regardless of maternal age and child functioning.

There is a substantial body of evidence lending objective support to behavioural intervention as an effective teaching method to ameliorate some ASD characteristics (Matson et al., 2009). Systematic teaching methods, such as behavioural interventions, are intended to improve language, social, play, and self-help skills in young children (Ontario Ministry of Child and Youth Services, 2006) with a goal of improving developmental trajectories to more closely match same-age typically developing peers. A recent media survey quantified that in the province of Ontario wait times for behaviour intervention ranged from one to four years (Gordon, 2012). In 2013, the Auditor General of Ontario further supported the need for behaviour intervention, noting more children were waiting to receive funded services than those currently receiving them (Office of the Auditor General, 2013). Currently in Canada there is no national ASD strategy. Under provincial ministries, provinces and territories organize and deliver services and supports. This investigation evaluated curricula delivered solely in the Greater Toronto Area (GTA), a densely urban area of Ontario.

Practitioners and researchers often recommend parent education as a complementary service to behaviour intervention programs (Steiner et al., 2012; National Research Council, 2001). Momentum for parent involvement in ASD treatment is growing (Matson et al., 2009) with the number of studies investigating parent education for children with ASD expanding. Following participation in education sessions parents have reported a wide range of meaningful benefits for their children such as reductions in maladaptive behaviour and improvement in communication, play, and social skills (Ingersoll & Dvortcsak, 2010). Additionally, parents report personal benefits of reduced stress and an increase in self-efficacy (Steiner et al., 2012). Ingersoll & Dvortcsak (2010) demonstrated that a specific parent education format—one-on-one parent-coaching—was as an effective teaching method to assist families with acquiring a significant range of skills; however, the required resources and staffing for this training method can be difficult for non-profit agencies. Such agencies frequently use group-based training as it is less time intensive and more cost-effective for the agency.

Methodology

Research Design

As the goal of this investigation was to gain practical input from a broad sample of parents a mixed-methods approach was fitting. Mixed-method research requires researchers to "collect data in such a way that the resulting mixture has complementary strengths and non-overlapping weaknesses" (Johnson & Christensen, 2004, p. 411). This investigation included two main data sources: transcribed content-rich recordings acquired through focus group discussions, and objective responses to statements included in a program-specific survey. This study used an author developed, program-specific survey to gain parent perspectives. Validated parent stress measures were considered; however, these tools would not have accurately captured this study's variables of interest. The primary researcher anticipated that,

when combined, the results from these two data sources would provide a complementary, comprehensive overview of parent perspectives.

Participants

Participants for this investigation were parents or caregivers of children with ASD who lived in the Greater Toronto Area. Participants were on a waitlist for their child to receive behavioural intervention and at minimum had completed four core education sessions offered through *The Parent Education Pathway*. A total of 141 potential participants (N = 141) met these criteria. Following research ethics clearance, participants were recruited through a pre-existing tracking database. Potential participants were invited to complete surveys mailed to them and were also invited to attend in-person focus group discussions. Sixty-one surveys were returned (rate of return of 43%; $n = 61$), a typical return rate for non-profit mail-out surveys (Hager, Wilson, Pollak, & Rooney, 2003). Sixteen of these parents attended focus groups ($n = 16$). See Table 2 for a description of education sessions included in *The Parent Education Pathway*.

Table 2: Parent Education Pathway

| <i>Phase Title</i> | <i>When available</i> | <i>Sessions Included</i> |
|--|--------------------------------------|--|
| <i>Getting Started</i> | following eligibility | Orientation Introduction to ASD |
| <i>Behavioural Approach to Parenting</i> | after completing Introduction to ASD | ABA Key Terms; Building ABA into Family Routines; Prevention & Redirection |
| <i>Preparing for IBI</i> | 12 months prior to service start | Introduction to Behaviour Intervention |
| <i>Partnering for Success</i> | during service | No specific sessions offered |
| <i>Preparing for School</i> | prior to transition from service | Introduction to Connections |
| <i>Special Topics</i> | after completion of ABA Key Terms | Daily Living Skills; Toileting; Nutrition; Play & Social Skills; Communication |
| <i>Information Sessions</i> | after completing Introduction to ASD | Parks & Recreation; Funding & Respite; Registration for school |

Data Collection Methods

This is a mixed-method study involving both qualitative and quantitative research. This study included a program-specific survey intended to obtain objective input from parents on key elements included in these education sessions as well as in-depth, content-rich insight obtained through focus group discussions.

Survey. The survey used for this study was a one-time, cross-sectional assessment investigating parental perspectives on resources and visual aids included in education sessions (Creswell, 2018). The survey required approximately 15 minutes to complete and included 35 first-person statements about three resources, four visuals, and the resource table present at each session. The researcher-developed survey focused on resources with statements specific to *Connectability.ca*, (an internet-based resource linking to audio workshops, visuals, and articles), *Parent Lending Library* (a collection of books, videos, and DVDs), and *RespiteServices.com* (an internet-based resource providing information on respite options available in Ontario). Refer to Figures 1, 2, and 3 for results of responses specific to these resources.

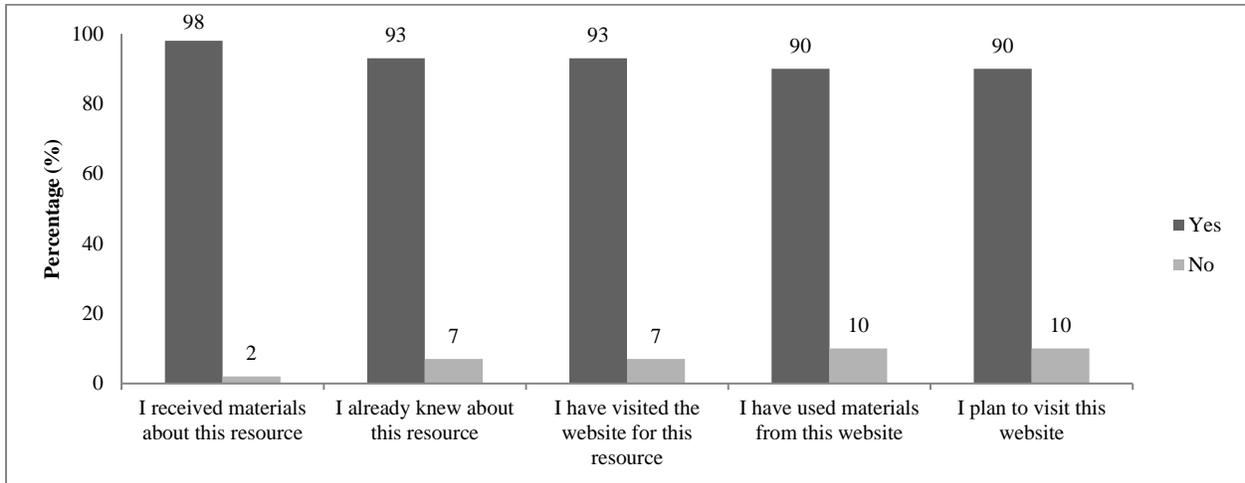


Figure 1. Parent Responses Specific to Connectability.ca.

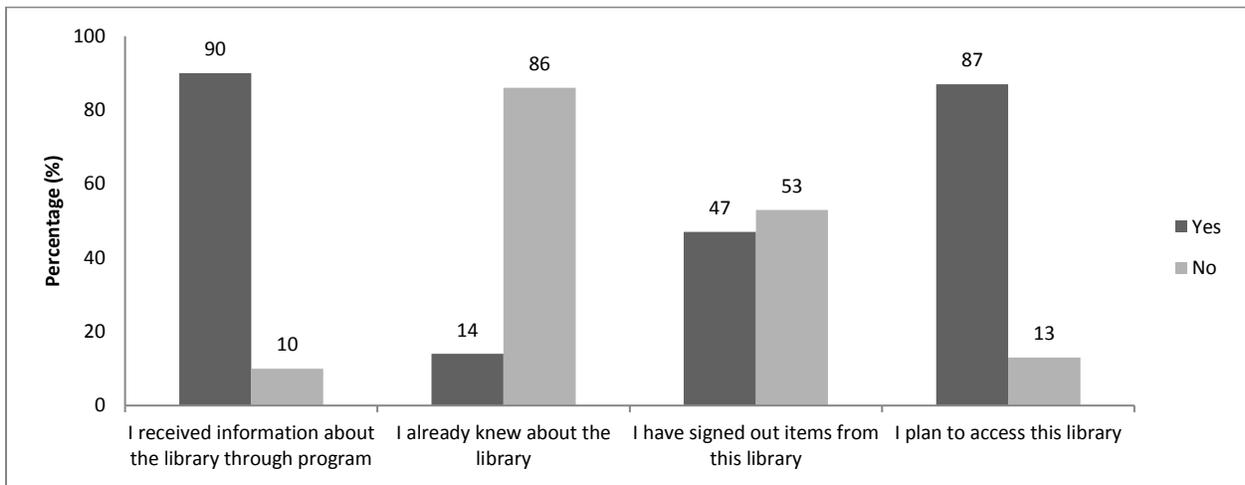


Figure 2. Parent Responses Specific to the Parent Lending Library.

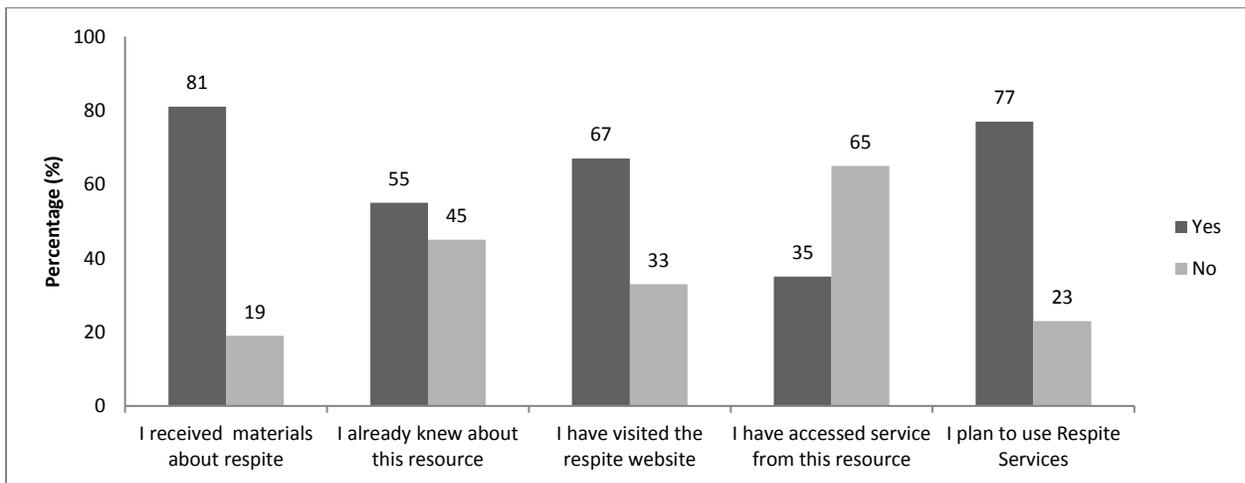


Figure 3. Parent Responses Specific to Respiteservices.com.

The survey also included statements specific to three visuals introduced in the education sessions entitled *Triad of Impairments* (a triangular figure used to help parents understand their child’s behaviour as it relates to social or communication deficits), *How to be an Advocate* (a wheel-and-spoke image listing various advocacy-related activities), and the *ABC Approach* (three circular images labeled Antecedent, Behaviour and Consequence used to introduce parents to behaviour analytic terminology and teaching methods). These images were selected as they visually represent core content covered during education sessions.

Focus Groups. Focus groups were held in four quadrants in the Greater Toronto Area; two in the north end of the city (N1 & N2), one in the East (E) and one in the West (W). Participant comments are identified with annotations comprised of the first initial of their quadrant and their participation number. Focus group size ranged from two to seven: 11 mothers and five fathers attended. Focus groups composed of a greater mother to father ratio aligns with previous related research findings. Davis and Carter (2008) determined that mothers have predominantly been the primary informants in studies of children’s development and family life. Discussions were semi-structured, moderated, audio recorded, and ranged in length from 70 to 235 minutes. Audio files were transcribed and uploaded to *Dedoose®*, a qualitative data analysis software (Lieber, 2009). Segments of text, 206 units in total, were coded and thematized into four major and three minor themes (Creswell, 2018). Major themes were defined as occurring in all four focus groups with at least 20 segments of text; minor themes were discussed in three focus groups with at least 15 segments of coded text.

Results

This investigation included two data sources: a program-specific survey and transcribed text compiled from four focus group discussions. The program-specific survey provided a large parent group the opportunity to comment on specific resources and visuals while focus groups offered in depth analysis of content and what might be missing.

Survey Results

Mothers completed 86% of the 61 surveys ($n = 51$) with fathers completing the remaining 14% ($n = 10$). Responses to survey questions related to *Connectability.ca*, *Parent Lending Library* and *RespiteServices.com* indicate that prior to attending these parent education sessions these resources were unfamiliar to the majority of parents (range: 7%–55%). However, following their attendance, a large majority of parents had accessed (or planned to access) such information (range: 77%–90%). From the positive parental responses (range: 72%–100%) to the survey statements specific to the *Triad of Impairments*, *How to be an Advocate*, and the *ABC Approach* visuals, it is evident these visuals were perceived as worthwhile tools for parental learning. Refer to Figures 4, 5, and 6 for a summary of responses.

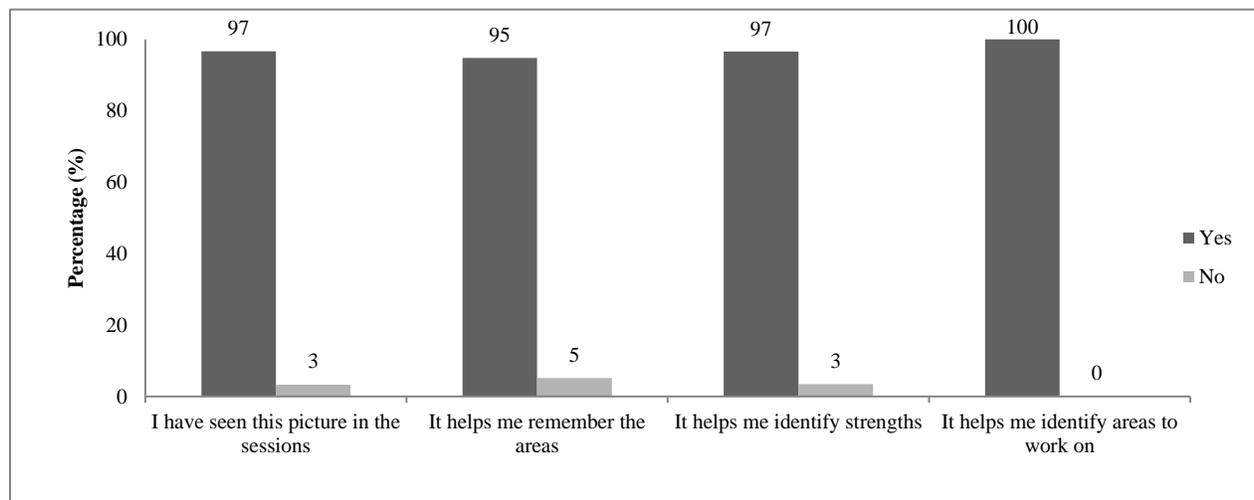


Figure 4. Parent Responses Specific to *Triad of Impairments* visual.

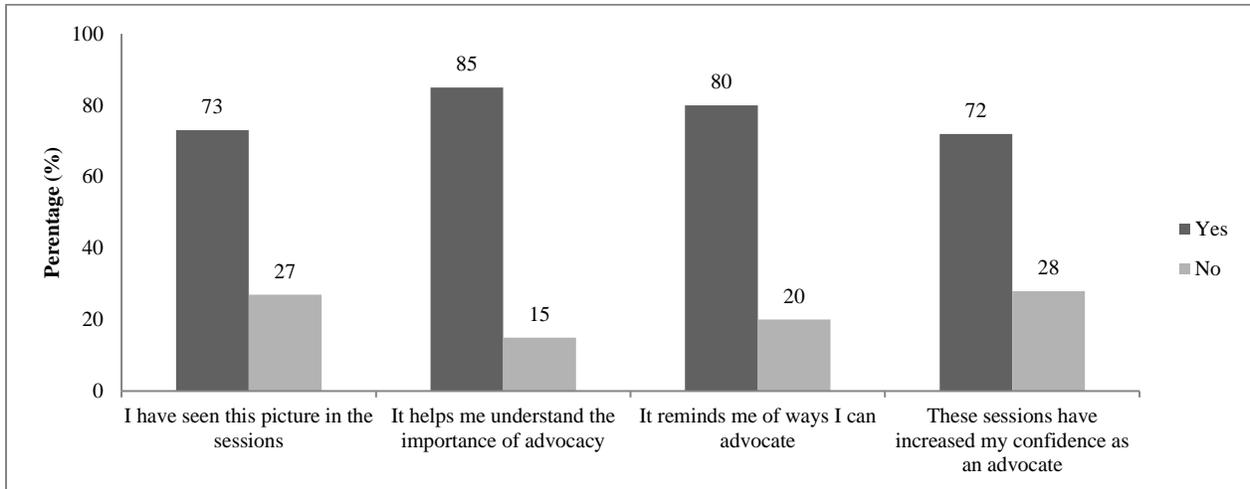


Figure 5. Parent Responses Specific to *How to be an Advocate* visual.

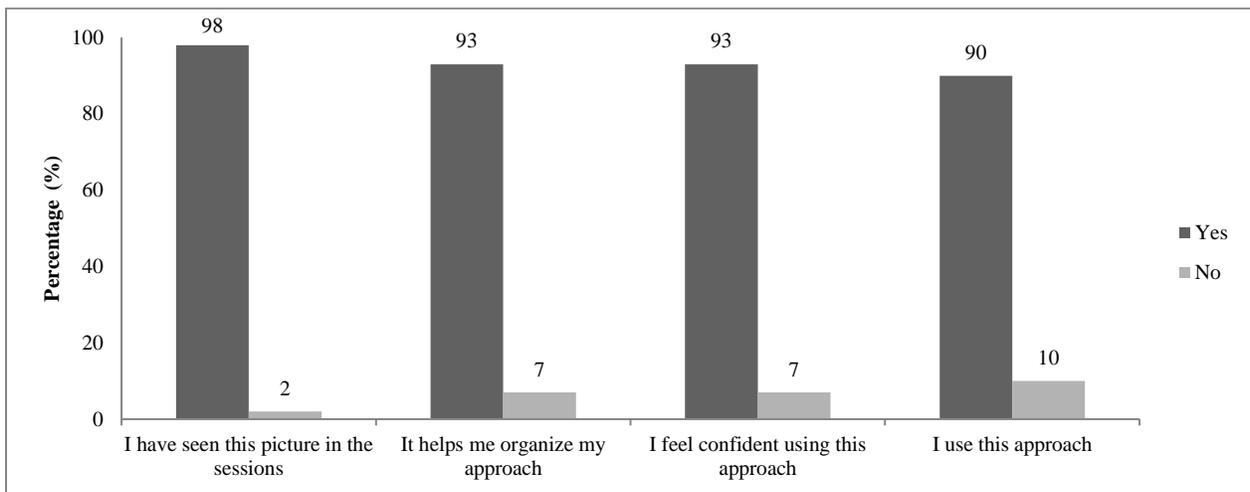


Figure 6. Parent Responses Specific to *ABC Approach* visual.

Focus Group Results

The following four major themes emerged during focus group discussions.

This is great, but something is missing. Parents appreciated the content and focus of the education sessions but highlighted specific resources and services they perceived as currently unavailable; most frequently, this was the absence of support groups. Participant E1, for example, described her feelings on the importance of that often-missing parental support:

As parents, there are not a lot of people who understand what we are going through. Like our personal friends and family members, they pretend that they do, but they really don't have any idea. That is where the parent support comes in.

Another noteworthy gap pertained to resources for siblings of children with ASD. Participants described the lack of such resources as a stressor. For example:

I think if you add a session about siblings. I know not everyone has siblings, but we have two older daughters and that has been a struggle trying to help them understand what is going on with their brother and why and how to deal with him. (Participant W2)

Additionally, participants described the need for training the whole family suggesting: “More resources for the family as a whole because it [ASD] affects the whole family and it can cause a lot of issues” (Participant N1).

Don’t just tell us—show us. Parents emphasized the importance of visuals including videos, increased use of real-life examples, and the opportunity to receive individualized coaching. Participant W5 explained that the video examples could be brief:

Just a 10-second clip, like this is a prompt, and a therapist engaging a child and seeing what that looks like ... not only do we get the material, and we’re talking about [it], but we’re visually seeing it being done.

Many parents also reported they would like more opportunity to receive feedback on strategy implementation. Participant E3 mentioned the importance of additional sessions dedicated to follow up “so we can share the actual reality with them [parent educators]. They tell us to do like this, but the actual reality of what we see at home, we should have a chance to discuss it later.” Participant W2 commented on coaching and individual check-ins that could have a personal touch:

It would have been nice if they checked in with people every week or so... I know it’s a lot of their time, but just like: *Hey, how is it going? How are you applying some of these concepts in your daily life with your child?*

We need more. A sizeable proportion of parents indicated that information sessions were useful, including a common sentiment was the idea of requiring *more*. Parents used the term *more* to reference the need for more information, more time to ask questions, and more time to talk to each other. Parents also had comments specific to the length of the sessions. One participant commented, “Two hours was too short, I would love a full day course or a weekend” (Participant N1). Parents also commented that they would like more opportunity to speak and share with one another. Participant W3 expressed that she would like “more opportunity for a little bit of interaction between the parents. I mean, it’s supposed to be a venue where you should be exchanging information.”

A parent’s perspective is worth a thousand words. It was apparent that hearing first-hand experiences and receiving direct guidance from other parents of children with ASD was invaluable. Two areas of importance emerged: receiving information directly from other parents and the ability to learn from so-called seasoned parents of older children with ASD. Participant W2 discussed the impact of other parent’s first-hand experience. She stated: “I am a parent so only another parent can give me the correct information.” Participant W3 elaborated, sharing, “someone who has walked in your shoes, their information is much more valuable than someone who has never had a child with autism who is lecturing to you about what you should be doing.”

In addition to the four major themes outlined above, three additional minor themes emerged.

Advocacy—It isn’t that simple. Sessions included information on, and the opportunity to discuss, advocacy. Participants shared that the responsibility of advocating was an additional stressor and is not a topic learned in one session. Participant W6 shared that advocacy “is very nice in theory and I guess it’s something to aspire to.” The majority of parents agreed that advocacy is best presented in smaller increments. Participant W5 discussed how broad the topic of advocacy spans: “[Advocacy] is not just one little topic; there [are] like six, seven different things. There is a lot there and it’s hard to kind of grasp.” Practitioners should pay careful consideration when determining how best to address the topic of advocacy with parents.

Lead us in the right direction. Parents emphasized a need for professionals to assist with system navigation and access to credible information. Participant W3 recognized the potential for parents to contact inaccurate and false information and described how professionals could assist, specifically mentioning vetted materials: “Dispelling myths is needed. Having someone go through with a fine-tooth comb—all those websites that are out there so parents don’t get confused and read the wrong information.”

Don't forget the finer details. A final minor theme related to room set-up and supplemental handout materials, details some practitioners may consider insignificant, however, it is apparent they can add significant value to the parent education experience. Parents unanimously agreed they prefer a handout that contains the same information included on slides with space available to write notes. Many parents expressed that they shared handouts with family members following sessions. It is necessary to note that at least once in all focus groups one or more parents described details of other education programs, often confusing content and delivery methods. In three of four focus groups, parents supported a round table seating arrangement over other styles such as classroom or theatre. During the first North focus group, Participant N4 mentioned, "When you think about it ... [a] circle is better because you can look at the person when they are talking. In rows, you can't." Handout material and room set-up should be carefully considered by those who plan and deliver parent education.

Discussion

The quantitative and qualitative findings from this investigation support literature claims that benefits are available to parents who participate in group-based education. Parents indicated that attending education opportunities with individuals in similar situations was a positive experience.

All parents who participated would recommend this program to other parents of children with ASD, supporting earlier researchers' claims that parents perceive a positive impact after participating in short-term education sessions based on non-standardized curriculum (Ingersoll & Dvortcsak, 2010; Samadi, McConkey, & Kelly, 2012). Statements shared through focus group discussions indicate that parents who participated in this education program perceived increased competence in parenting and enjoyed being a part of a social network. These findings are similar to those reported by Samadi, McConkey, and Kelly (2012), who demonstrated through a pre-post crossover design a significant improvement in parental ratings of health, stress, and family functioning following parent's participation in a 10-hour group-based education course.

Parental Stress

This study further identifies the stressful and adverse experiences of parents of children with ASD. The term "stress" was mentioned 12 times by mothers, fathers, parents waiting to receive service, as well as by parents of children currently receiving services. In this investigation, fathers were as likely as mothers to reference stress, possibly broadening Steiner et al.'s (2012) notion of parental stress to include fathers. Parents did not allude to any child-specific characteristics that contributed to their stress, potentially indicating that their perception of societal factors—such as lack of community resources, lengthy waitlists for service, challenges explaining ASD to family members, and social isolation—may be a contributing factor to parental stress.

Behavioural Learning Theory

Survey responses to questions specific to the *ABC Approach* visual indicate that after attending these education sessions parents perceived increased confidence in their ability to use operant conditioning during home routines. Jang et al. (2012) reported that providing parents with education and training on principles and procedures of ABA could assist them in better understanding their children's intervention programs as well as increase the likelihood that parents could carry over behavioural teaching in the home and community. This investigation aligns with literature that demonstrates the value of providing parents with education on behaviour analytic teaching methods, especially antecedent prompting and positive reinforcement (Matson et al., 2009).

Self-Efficacy

An individual with a strong sense of efficacy will persevere when faced with personal challenges (Bandura, 1977). Parental self-efficacy relates to a sense of competence and capability in the parenting role with competence impacted by direct feedback from others. During focus group discussions, many parents requested the opportunity to receive performance-specific feedback on their ability to implement behavioural teaching strategies in the home. It is plausible that parents of children with ASD are motivated to adjust their feelings of self-efficacy and initiating parent coaching is a suitable strategy to ameliorate this mindset.

Implications

This research can benefit practitioners as well as others involved in providing education and supports to parents of children with ASD, particularly those who modify behaviours using ABA technologies. These results document the importance of content and structure, short-term education programs, parent coaching, service organization, and advocacy.

Content and Structure

The framework of this program was captured under the *Parent Education Pathway* and was organized in a deliberate manner with an overall objective of assisting parents to be *informed, aware, active, and engaged* in their child's learning. These key words appeared often throughout the sessions. When reviewing the literature specific to parent training formats and methods, it did not appear that other content developers of education programs for parents of children with ASD had prioritized important parent attributes when organizing their curriculum. Going forward, individuals responsible for developing curriculum could identify specific skill areas to target, identify a related attribute, and refer to these identified terms frequently throughout the curriculum. Structuring content in this way assists parents and educators to remain focused on the objectives of the program.

Knowledge. Content focused mainly on informing parents about diagnostic features of ASD as well as evidence-based interventions, primarily Applied Behaviour Analysis. Parents agreed that through participation they perceived themselves as more knowledgeable about ASD and ABA. This parental report lends further support to include content specific to core deficits, etiology, and effective intervention methods when developing education sessions.

Problem-solving. A number of visual tools were included to assist parents with applying behaviour analytic principles to everyday parent-child interactions. Learning how to approach problematic situations and recognizing the relationship between antecedent, behaviour, and consequence is a useful problem-solving skill for parents. Survey results demonstrated the vast majority (93%) of parents found the *ABC Approach* visual useful with helping them organize their teaching. The comments and survey responses specific to this problem-solving approach indicate that parents who feel empowered to problem solve may experience less stress (Hedderly, Baird & McConachie, 2003).

Short-Term Education Programs

The education sessions assessed as part of this investigation totaled approximately seven hours of group-based training. Parents unanimously agreed that participating in these sessions made parenting their child with ASD easier supporting Ingersoll and Dvortcsak's (2010) claim that parents who participate in education sessions report improved parent-child interactions. These findings are similar to those reported by Samadi, McConkey, and Kelly (2012), who demonstrated a significant improvement in parental ratings of health, stress, and family functioning following participation in a 10-hour group-based education course.

Parent Coaching

This study demonstrated that parents of children with ASD were keen to adjust their perceptions of self-efficacy. Many parents requested the opportunity to receive direct, child-specific feedback on their ability to implement behavioural strategies in the home. Literature reports highly favourable results when a coaching component is included (Ingersoll & Dvortcsak, 2010). Prior to including coaching into parent-training platforms, parent educators need to consider that skills required to coach parents are significantly different than skills required to lead didactic sessions. Organizations would need to evaluate if resources are available to develop this skill-set with staff. Another factor to consider is the added expense attached to parent coaching, as this training is delivered in a one to one format. From a service model perspective, agencies may not be able to serve as many clients through parent coaching as opposed to group training formats. Given the favourable observations noted in the literature and the frequent mention of coaching during discussions, future developers could explore offering parent coaching following parent training.

Service Organization

A key finding of this investigation was the potential for parents to confuse or overlap objectives from various programs and services. Practitioners could do more to assist parents with organizing the information attached to the variety of services and supports they are accessing. Education programs could adopt key messages or simple program-specific descriptions to be included on printed material (e.g., bookmarks, templates, letterhead). This simple branding strategy may assist parents with recalling unique objectives attached to a specific program. Another suggestion is to allocate a brief amount of time at the beginning of a session for parents to discuss other programs and services, providing an opportunity for educators to outline specific objectives attached to the current program as well as highlight similarities or differences between programs. Going forward, organizations tasked with planning and delivering education opportunities for parents could explore the benefits of a parent advisory group.

Advocacy

The *Parent Education Pathway* adopted an advocacy framework based on the work of Martin (2010) and outlined in her book, *The Everyday Advocate*. When discussing this topic, it was apparent that Martin's work was overly theoretical and did not sufficiently describe specific parent activities or devote an adequate amount of time on coaching parents to become skilled advocates. This recognition that advocacy is a comprehensive topic aligns with previous literature descriptions. Trainor (2010) labeled parent advocacy and its expected outcomes as an enormous responsibility. Going forward, curriculum developers need to be sensitive to the number of activities this already taxed population is being asked to adopt. Approaching the topic of parent advocacy in smaller, manageable tasks, and providing ample time and opportunities to practice and discuss advocacy-related barriers should be prioritized.

Future Research

A potential area for further exploration would be to investigate whether parent participation in education prior to their child beginning intensive service leads to increased involvement during their child's treatment. Creating conditions for the highest level of parent involvement possible is an important factor to consider as short-term treatment relies heavily on parent mediators to maintain acquired gains. This study demonstrated that parents feel confident using a behaviour analytic approach when teaching their children. It may be of interest to some behaviour analysts to assess the accuracy with which parents are using this teaching approach in the home and the community.

Limitations

This investigation gathered specific information on parents' perceptions of curricula offered through a community-based program in an urban city in Ontario and results should not be broadly interpreted to represent perceptions regarding parent education in general. It is plausible that the perceptions of this sample of parents are not representative of all parents of young children with ASD. The small number of focus group participants may impact the generalizability of the results and the level of English proficiency required to comprehend the mailed survey may have prevented some parents from responding.

Conclusion

This study assessed newly developed curriculum offered through a community-based program to parents of children with ASD. This investigation inquired if participation in education sessions assisted parents in being (more) active, aware, and involved in their children's development. Results support that following attendance parents were better informed on characteristics of ASD, aware of available community resources and how to access them, and had perceived competence in their abilities to use behaviour analytic methods to support their children's learning. Many of the themes uncovered in this investigation align with and add to the experiences of parents of children with ASD previously reported in the literature. Parents articulated a variety of suggestions to enhance curriculum and parent experience. Future research could revisit assessing the perspectives of future participants following implementation of these recommendations.

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