# Rethinking parents as therapists for children with ASD: Adding stress to the family system

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Current recommendations for interventions involving children with Autism Spectrum Disorder (ASD) include parent involvement in implementing therapy. The reasons for this include increased generalization and cost-effectiveness. However, research has not sufficiently addressed the possibility that placing an additional role of therapist on parents of children with ASD contributes to increased stress. This paper examines some of the main arguments for parents acting as therapists. Specifically, research demonstrates that the role of parent as therapist is not the only option for increasing generalization, and that this form of therapy implementation may not be cost effective for the family when considering loss of income. Possible implications are discussed, including loss of income, increased time demands, negative effects on relationships between family members, and emotional strain. Future research areas that focus on understanding and addressing the possible negative impacts of parents taking on the role of therapist are suggested, including increased focus on interventions in inclusive childcare settings.

Keywords: Austism Spectrum Disorder, parent-mediated intervention, stress

One of the most effective forms of therapy for children with Autism Spectrum Disorder (ASD) is intensive early behaviour intervention (EIBI) occurring during the toddler and preschool years (Reichow, 2012). These approaches are not without challenges, including difficulty with generalizing skills learned during therapy and the high cost of treatment. Recent literature has emphasized the importance for caregivers to become involved in implementing interventions to address both of these concerns (Pickles et al., 2016; Schreibman et al., 2015). However, there are other effective ways to overcome these challenges that do not place the role of therapist on the parents. Researchers have often neglected to address the increased stress or potential negative outcomes that may result from parents acting as therapists (Karst & Vaughan Van Heck, 2012). Of the studies that do address parental stress in parent-mediated interventions, stress is often examined as a function of the success of treatment and not directly in relationship to the additional therapist role demand of the intervention (Reichow, 2012; Smith, Flanagan, Garon, & Bryson, 2015).

The family system is often strained when raising a child with autism spectrum disorder (Karste & Vaughan Van Heck, 2012; Kuhn & Carter, 2006). Placing additional demands on the parents may exacerbate existing struggles, including loss of income, martial discord, and negative sibling relationships (Fletcher, Markoulakis, Bryden, 2012; Rivers & Stoneman, 2003; Roper, Alfred, Mandleco, Freeborn, & Dyches, 2014). As such, research needs to include a

focus on programs that address both the needs of the child and the family system, such as those that imbed intervention in daycare settings (Magiati, Charman, & Howlin, 2007).

This paper will discuss several factors related to parent-implemented therapy. This will include the reported benefit of increased generalization but that is not specific to parents acting as therapists, and a cost-analysis demonstrating the financial strain placed on families raising children with ASD. Finally, multiple stress effects on the family are examined, which may arguably be exacerbated when parents take on the role of therapist. The paper concludes with a recommended alternative and call for further research that does not require therapy be implemented by a child's caregivers.

## Generalization of Skills

Applied behavioural analysis (ABA) based therapies termed as naturalistic developmental behaviour interventions (NDBIs) are currently recommended to improve generalization skills in young children with ASD (Schreibman et al., 2015). Children with ASD have difficulty with generalization (Barton, Lawrence, & Deurloo, 2011), and forms of early intervention such as discrete trial teaching do not show as much promise as NDBIs in addressing this specific problem. NDBIs allow for intervention using ABA principles to occur in the context of the child's daily routine (Stiener, Koegel, Koegel, & Ence, 2011), and are more flexible in their design and implementation (Chang, Shire, Shih, Gelfand, & Kasari, 2016) compared to most early intensive behaviour interventions (EIBIs). Unlike interventions that explicitly teach skills outside of their natural context, these programs imbed instruction in the child's daily routine using ABA principles, allowing for increased generalization. EIBI programs, including NDBIs such as such as Pivotal Response Training (Smith, Flanagan, Garon, & Bryson, 2015) and JASPER (Kasari, Gulsrud, Paparlla, Hellemann, & Berry, 2015), often recruit parents to become involved as therapists in the implementation of the interventions. Research cites the reduced cost (Stiener et al., 2011), and ease at which parents can imbed interventions within the daily routine (Pickles et al., 2016) as reasons for parents to take on the role as therapist. Additionally, parents are able learn effective teaching and interaction methods that help to improve their autism symptoms (Kasari et al., 2015). This approach has also been shown to be effective in improved generalization of skills in young children with ASD (Kasari et al, 2015; Smith et al, 2015; Stiener at al, 2011).

Improved generalization can also occur without the involvement of parents acting as therapists. Research has demonstrated that interventions can be effectively carried out in daycare and classroom settings by multiple individuals, including teachers and support workers (Barton et al., 2012; Kaale, Smith, & Sponheim, 2012; Sainato, Morrison, Jung, Axe, & Nixon, 2015). In fact, interventions taking place in the same environment as typical developing peers is suggested to increase social skill generalizability compared to one-to-one therapy environments (Chang et al, 2016). Therapies implemented in inclusive settings, such as a daycare or classroom, allow for greater opportunity to develop social skills and peer relationships. Peer-mediated interventions, which has demonstrated promise in the generalization of social skills (Chang & Locke, 2016), is only possible within an inclusive environment with typically developing peers. Research conducted by Sainato et al. (2015) has demonstrated that specific therapies within an inclusive kindergarten setting can be con-

ducted with high fidelity to the program and with improvements in core deficits and academic development. Given the feasibility of implementing therapy in an inclusive childcare or academic setting and the increased generalizability of social skills, this potential intervention environment deserves more consideration in research.

NDBIs often involve targeting multiple skills (e.g. play skills, language, daily routines), data collection, and procedures that require their own instruction on implementation (Chang, et al., 2016; Schreibman et al., 2015). That makes acting as a therapist much more complicated than simply using certain teaching or communication techniques. Research shows that parent training is helpful in improving autism symptoms (Steiner et al., 2011), demonstrating that it is possible for parents to learn to provide the care their child needs to support their learning without acting as therapists. Parenting training may increase parents understanding of how best to teach their child, such as how to move through a daily routine using prompting procedures learned during parent training, for example. Parents acting as therapists, on the other hand, may have to collect data on the success rate and level of prompts used in each step for the same routine. Even though NDBIs are more flexible than ABA interventions using discrete trial teaching (Reichow, 2011), parents still cite the structure required in the interventions as a barrier to implementing them in the home (Pickard, Kilgore, & Ingersoll, 2016). Parents can, and should, be given the tools necessary to make them more effective parents; however, they can be given this information so that they can support their child's development without taking on the role as therapist. JASPER, a form of NDBI, has been shown to be effective when implemented by parents as well as in daycare settings (Chang et al., 2016), demonstrating that there are options outside of using parents as therapists when conducting interventions. Therefore, it may be unnecessary to recruit parents as therapists for NDBIs to be considered effective.

## Cost Analysis

The high cost of evidence-based interventions for young children with ASD is another reason given for parents to take on the role as therapist for their child (Schreibman et al., 2015, Steiner et al., 2011). The recommended amount of early intervention that a child should receive per week ranges from 20 to 40 hours minimum of a form of ABA therapy (Reichow, 2011). Children with ASD receive individualized programs designed by a certified behaviour consultant (BC), and then implemented by behaviour interventionists (BIs). Additional professionals, such speech language pathologists (SLPs), occupational therapists (OTs), and physiotherapists (PTs) are also sometimes involved (Kaale et al., 2012). The fees of these professionals, according to British Columbia's Ministry of Children and Family Development (2017), are as follows: BCs, $70-$110 per hour; BIs, $10-$20 per hour; SLPs, $105-$130 per hour; OTs, $90-$120 per hour; and PTs, $75-$85 per hour (p. 22).

To approximate the average monthly expenses for therapy, the mean average of all professional fees, the mean average of recommended therapy hour per week (30 hours), and included four hours of BC services, while excluding SLP, OT, or PT. The average monthly expenses for therapy can be approximated at $2,160, or $25,920 annually not including travel expenses. A parent acting as therapist for 10 of those hours per week, rather than a BI, would provide a family with savings of $600 per month, or $7200 per year. Families raising a child with autism often report stress about

their financial situation (Fletcher, Markoulakis, & Bryden, 2012; Karst & Vaughan Van Heck, 2012), possibly leading them to decide to take on the additional role as therapist to alleviate financial strain.

The surface appearance of cost-effectiveness in parents taking on a therapist role for their child with ASD ignores many hidden costs such as travel time and costs, and lost wages. One study found that children with ASD receive an average of 14.85 hours per week of 5.43 different types of services in early childhood (McIntyre & Barton, 2010). If one considers the additional time it takes for parents to drive their child to various appointments, as well as the time spent coordinating care and maintaining contact with various professionals, parents likely spend, on average, over twenty hours a week devoted to their child's therapy. Many parents cannot balance these demands with full-time employment, resulting in one parent, often the mother, electing to leave their job to act as primary caregiver (Fletcher et al., 2012; Jellet, Wood, Giallo, & Seymour, 2015). Caregivers of children with ASD report many employment-related sacrifices that they have made due to the needs of their children, including lost promotions, reduced hours, and accepting lower paying jobs that provide better hours to suit the needs of their child (Fletcher et al., 2012), in addition to leaving the workforce entirely.

A study conducted in Australia found that nearly 90% of the median annual cost of ASD to a family was directly related to lost productivity at $29,200 (Horlin, Falkmer, Parsons, Albrecht, & Falkner, 2014). The remaining costs ($5,700) attributed to therapy, medical, and travel expenses. In the study, this lost productivity was calculated based on the country's median full-time income ($48,864) and the reported full-time employment units lost by each participating family. Proportionally, the median annual cost of ASD was 59.76% of the total average median family income. If one were to calculate the lost productivity experienced by families in Canada raising a child with ASD using the same proportions with the country's 2015 median full-time income of $55,600 (Statistics Canada, 2016), the total would be $33,226.56. This calculation is a rough estimate, but is reasonable considering the similar economic and political structures of the two countries (Hunkar, 2009), as well as similar funding and forms of available ASD interventions (Horlin et al., 2014). When one adds the approximated annual cost of therapy outlined earlier ($25,920 + $33,226.56= $59,146.56) and then factors in the $22,000 per year funding provided by the government of British Columbia for children with ASD under age 6 (Ministry of Children and Family Development, 2017), the total cost to families of therapy and lost production is approximately $37,146.56. This approximate cost does not include any SLP, OT, or PT services, and does not factor in travel expenses, medical treatments, or alternative therapies.

Given the large annual cost of treatment incurred by families raising a child with ASD, it is reasonable to assume that some parents take on the additional role of therapist to alleviate some of the financial strain put on the family. Simply having the parent not take on the roll of therapist does not always decrease the loss of productivity, as at-home interventionists often require the parent to remain in the home while the BI or other professional conducts the therapy session. One option that addresses reducing loss of productivity expenses is the conduction of therapy in childcare settings. Interventions conducted in inclusive childcare settings may potentially allow caregivers to work while their child receives the recommended amount of therapy per week. Therapies offered in this type of setting may also alleviate

some of the travel time and associated costs incurred when attending multiple therapy sessions outside the home.

### Family Stress

Little research has been conducted to directly assess the impact that having a parent take on the role as therapist has on individual levels of stress, mental well-being, or the larger family system. However, the underlying stress of families of children with ASD has been well studied. In one survey, parents indicated stress levels above and beyond the ceiling of the stress measurement used (Kasari et al., 2015). Families report numerous unmet needs which include: a break from responsibilities (54.5% of respondents), time alone with their partner (64.4%), help remaining hopeful for their child's future (61.4%), and help dealing with fears about their child's future (63.4%) (Brown et al., 2012). This indicates that parents of children with ASD feel overwhelmed and under-supported in dealing with their child's disability. In addition, the time of diagnosis has been identified by parents as being one of the most stressful periods of their life (Kuhn & Carter, 2006). This is likely because parents are coming to terms with their child's diagnosis, while simultaneously taking on the role as care coordinator for their child's therapy (Hastings et al., 2005). Taking on the role of therapist in their child's intervention at this time would serve to add to the already overwhelming level of stress that parents experience. Parents should only be asked to take on the additional role of therapist if absolutely necessary, and then only with due consideration of the family system and the needs of all individuals.

### Parental Relationship

Although mothers often act as primary givers and report high levels of stress, fathers are not exempt from similar negative impacts of raising a child with ASD (Jellet et al., 2015). The stress and depression experienced by mothers of children with ASD has been shown to increase the level of stress and depression in fathers (Jellet et al.,2015). Two parents who are highly stressed are at greater risk for turmoil within their marriage. Parents of children with ASD are at greater risk for divorce than are parents of neurotypical children from the child's birth into early adulthood (Hartley et al., 2010). It is suggested that the burden of caring for a child that is unable to care for themselves as they mature contributes to the divorce rate amongst parents of children with ASD. A rate that is double that of the typical population (Hartley et al., 2010). Adding an additional burden of acting as therapist may serve to increase stress not just for the primary caregiver, but for their partner as well, which may increase the likelihood of marital discord and possibly divorce.

### Siblings

Parents of children with ASD are not the only ones impacted by the increased demands associated with caring for a child with a disability; sibling relationships have also been shown to be negatively affected (Hasting et al., 2005; Roper et al., 2014). This may be because of the direct interactions between siblings, or because of the resentment felt by the neurotypical sibling due to the parents attending to the child with ASD at the perceived expense of the sibling's own needs (Jellet et al., 2015). One study indicates that over 50% of mothers and 70% of fathers believe that early interventions conducted in the home environment negatively impacted the child's sibling, with over one third of siblings not getting as much attention

as the child with ASD (Grindle, Kovshoff, Hastings, & Remington, 2009). If parents are then required to actively participate as therapists for interventions in the home, this would decrease their availability to the child's sibling(s) and potentially further negatively impact both the child-sibling relationship and the parent-sibling relationship. Research has demonstrated that perception of sibling preferential treatment and jealousy of the sibling is linked to maladaptive behaviours in adolescents (Loeser, Whiteman, & McHale, 2016). Even if the parents acted as therapists for only a few hours a week, those few hours could have a lasting effect on a sibling who is already feeling ignored if it results in perceptions of sibling preferential treatment or increased jealousy.

## Therapy Challenges

It has been shown that parental stress is influenced by the challenging behaviours of their child with ASD, and not the severity of autism symptoms or lack of adaptive behaviours (e.g., activities of daily living) (Hastings et al., 2005; Jellet et al.,2015; Roper et al., 2014). Additionally, the exposure to challenging behaviours without opportunities for breaks provided by therapy sessions being conducted by others does have the potential to increase parental stress. A bidirectional influence of parental stress and challenging behaviours has proposed that parent fatigue, possibly in part due to a child's challenging behaviours, resulting in difficulty managing the behaviour, which in turn escalates the behaviour (Seymour et al., 2012). Parents acting as therapists, who would otherwise be given a break from directly managing the challenging behaviours, may experience increased stress and fatigue that could act to increase the severity of the behaviour. The benefits of even 1 hour per week of respite for parents with ASD includes reduced stress and increased marital quality (Harper, Dyches, Harper, Roper, & South, 2013). It is possible that these benefits may also occur when parents are provided with breaks from directly teaching and managing challenging behaviours. Interventions conducted by professionals rather than the parents allow for these small breaks from directly managing challenging behaviour, while requiring that the parents act as therapists removes a potential opportunity for reducing stress.

Interestingly, when a parent is highly stressed, the positive impact of therapeutic interventions is negated (Osborne, McHugh, Saunders, & Reed, 2008). This indicates that even the best therapy, if implemented within an already stressed system, has the potential to have little to no impact. It does not make sense to increase the stress on the family system with the justification of improving autism symptoms when that increase in stress may serve to negate any improvements. The goal of therapeutic interventions in children with ASD is improvement in symptoms and adaptive functioning, and the negating effect of parent stress on these improvements is one that deserves due consideration when designing and implementing these therapies. A study conducted by Smith et al. (2015) demonstrated no effect on parental stress despite improvements in core autism symptoms. Therefore, the potential improvements in autism symptoms and reduction of challenging behaviours that may be experienced when the parents act as therapists may not mitigate the potential negative impacts.

In some families raising a child with ASD, stressors such as chaotic family environments, unstable housing, and unmet basic needs serve as additional barriers to parents implementing therapy in the home (Pickard et al., 2016). A better approach, providing more

equitable opportunities for success for children from any background, would be one that provides interventions outside of the family home. An inclusive daycare setting, for example, provides a learning environment removed from experiences of parental stress and barriers to therapy, as well as allowing for generalizability of skills amongst their peers. Generalizability to the home environment may require parent training to extend techniques into the home environment to support teaching that is occurring elsewhere. However, as discussed earlier, parent training differs from parents acting as therapists, and helps to improve parents' confidence and efficacy (Steiner et al., 2011) without burdening them with the role as therapist.

## Individual Caregiver Stress

Recruiting parents as therapists in their child's intervention has potential negative impacts on parent's sense of efficacy. Parents have reported feeling lost and defeated when unable to effectively parent their child (Robinson, York, Rothenberg, & Bissel, 2015) prior to their ASD diagnosis. It is possible that this sense of defeat may also occur if a parent feels ineffective as a therapist for their child after diagnosis. A parent's feeling of guilt has been negatively associated with a sense of self-efficacy in mothers of children with ASD, which is in turn associated with maternal well-being, levels of depression, and parenting stress (Kuhn & Carter, 2006). Therefore, if a parent acts as therapist for their child, they may experience a loss of sense of self-efficacy if there is a lack of improvement. This in turn has the potential to increase stress and depression for the mother. When compared to peers of non-depressed mothers, typically developing young children with depressed mothers more frequently displayed insecure attachment, lower cognitive abilities and social skills, and increased behaviour problems at 24 months of age, and less developed language at 36 months (Wang & Dix, 2013). Maternal depression has also been noted as a general risk factor for both internalizing and externalizing behaviours in later childhood (Fanti & Henrich, 2010). Therefore, maternal depression, possibly be exacerbated by the additional role of therapist, has the potential to negatively influence the developmental trajectory of both the child with ASD and their siblings.

Several articles addressing the stress that parents experience when they have a child with ASD recommend that parents are provided with a form of support: psychoeducation (Kasari et al., 2015), counseling, or utilization of social supports (Osborne et al., 2008; Jellet et al., 2015; Hastings et al., 2005). Surprisingly, none offer the possibility of reducing the load placed on these families to reduce overall stress. Parents are already overwhelmed by the amount of time and energy one must devote to a child with ASD, and are potentially neglecting the needs of their partner, their other children, and themselves to provide the best care for their child. They likely do not have the ability to put additional time and energy forward to provide therapy to their child as well. If the role of therapist can be removed from parents, allowing them more freedom to focus on their many other roles, then their stress could be greatly reduced. Eliminating a role is much easier than designing and implementing new therapies to address the stress that a parent is going through; new therapies, ironically, could actually increase stress by adding yet another appointment to an already overstretched family calendar.

## Conclusions

One solution that addresses the

demand for cost-effective treatments that are easily generalizable, but do not require caregivers to take on the additional role as therapist, is to conduct evidence-based early intervention therapies in daycare. Despite the challenges that one may associate with inclusive care settings, several social benefits for the child and their peers, as well as increased quality in instruction, have been demonstrated (Carrington et al., 2016). Studies of interventions conducted in both preschools (Baron et al., 2012; Chang et al., 2016) and kindergarten (Sainato et al., 2015) have demonstrated that effective therapy conducted with high fidelity is possible; however, more research is needed.

A focus on intervention in inclusive childcare settings opens many possible research areas. These include intervention designs that are best suited to different childcare settings, specific family factors that may indicate the need for a childcare-based intervention, cost-effectiveness of service delivery, and family and parental quality of life measure comparisons between intervention settings. If successful, research may act to influence policy makers in government, leading to changes in the funding and accepted forms of service delivery that may add benefit to both children with ASD and their families. With the many possible sources of stress for families raising a child with ASD, it is important that the focus of autism research be on creating a system of support and treatment that equally serves parent and child, rather than one at the potential expense of the other.

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