Parents' assessments of their child's autism-related interventions

Daniel Shepherd*, Jason Landon, Sonja Goedeke, Kelly Ty, Rita Csako

Department of Psychology, Auckland University of Technology, 90 Akoranga Drive, Northcote, Auckland 0627, New Zealand

ABSTRACT

Background: Interventions for autism spectrum disorders (ASD) are typically evaluated on the basis of symptom-focused outcome measures. These measures tend to be clinician rated and derived in clinical studies, whilst broader parental experiences are often neglected.

Method: Here we report a study of 585 parents of children diagnosed with ASD, focusing on their assessments of their child's ASD Interventions, and how they are perceived to impact parental stress.

Results: Overall, high proportions of parents reported disengagement with treatment. The highest completion rates were evident with speech-language therapy, and the lowest with intensive applied behaviour analysis (iABA). However, parents reported the highest expectations, satisfaction and stress reduction with iABA. These paradoxical findings are perhaps due to the relative cost and lack of funding directed towards iABA.

Conclusions: Our research suggests that parental expectations and the factors influencing them are worthy of further investigation. More pertinently, parental ratings of intervention effectiveness along with current intervention engagement are a vital and often overlooked component of understanding the effects of interventions on children with ASD and their families.

1. Introduction

Determining an accurate symptom profile of a child with autism spectrum disorder (ASD) is important not only for diagnostic purposes, but also for ASD-related intervention choices and the evaluation of such interventions. Assessing a child's ASD core symptoms can be undertaken through formal clinical assessments or by parental reports, the former being considered 'objective' and the latter 'subjective'. From a psychometric standpoint, practitioners and researchers champion 'gold standard' objective measures that are considered bias-free and more accurate. From a service delivery perspective, the use of objective standardised tests by a trained administrator allows the impression of equitable testing across children, important when diagnostic decisions have funding consequences. However, a reluctance of practitioners to utilise parental assessments of their child's ASD symptoms may come at the cost of incremental validity, whereby parental ratings may potentially inform clinical decision making and lead to more accurate diagnoses and better intervention evaluations.

There is little guidance in the literature as to which of the objective or subjective approach best captures the characteristics of the child being assessed (Miller, Perkins, Dai, & Fein, 2017). Parental assessments could be conflated by a multitude of factors, including care-related self-esteem, parenting stress levels, and the existence of mental health issues (Karst & Van Hecke, 2013; Miller et al., 2017). Additionally, parents may underplay the severity of their child's symptoms due to denial (Ozonoff et al., 2011), or overplay them by focusing on their child's more problematic behaviours (Zapolski & Smith, 2013). The case of secretin use in the late 1990′s is

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* Corresponding author at: Department of Psychology, Auckland University of Technology, Private Bag 92006, Auckland, 1142, New Zealand.

E-mail addresses: daniel.shepherd@aut.ac.nz (D. Shepherd), jason.landon@aut.ac.nz (J. Landon), sgoedeke@aut.ac.nz (S. Goedeke), wyv1287@aut.ac.nz (K. Ty), rita.csako@aut.ac.nz (R. Csako).

a disquieting example of how parents can exhibit bias when judging treatment effectiveness (Sandler, 2005). However, far from providing an accurate assessment of a child's core symptoms, objective testing undertaken in the clinical environment is also vulnerable to compromised validity. Here, child behaviour may change due to an unfamiliar environment, for example, reduced verbal behaviour during a language test. Furthermore, ASD-related problem behaviours such as defiance or indifference may likewise limit the validity of standardised tests that were originally designed for neurotypical children (Nordahl-Hansen, Kaale, & Ulvund, 2014).

A plethora of studies have found links between parenting stress and both ASD core symptoms (Lecavalier, Leone, & Wiltz, 2006) and ASD-related problem behaviours (Huang et al., 2014). The negative impacts that ASD has on functioning can be lessened through the provision of evidence-based Interventions, most effectively when applied at the onset of the disorder (Caron, Bérubé, & Paquet, 2017; Salomone et al., 2016). However, what constitutes 'evidence-based' interventions' in the ASD literature is disputed (Rogers & Vismara, 2008), and some have appealed for improved approaches to the evaluation of outcomes measures across ASD interventions (Odom, Boyd, Hall, & Hume, 2010; Bulkeley, Bundy, Roberts, & Einfeld, 2013). As a general rule, ASD interventions are evaluated in terms of symptom-focused outcome measures, while the parental and family factors that may determine the long-term success of the intervention are typically side-lined (Karst & Van Hecke, 2013). Murray, Ruble, Willis, & Molloy (2009) maintain that the contextual nature of ASD problem behaviours requires the involvement of multiple assessors, including parents, when assessing a child's function across different settings. It can be argued that the same should hold for intervention evaluation, particularly if the generalisability of outcomes are being appraised.

The best-practice evaluation of an intervention consists of randomised control designs involving comparisons of outcome measures between an intervention and matched control groups obtained under 'ideal' conditions (Gartlehner et al., 2006). Therapeutic outcome measures usually focus on child symptoms as rated by clinicians, and the judged *efficacy* of an intervention is said to be 'evidence-based'. An alternative approach is to measure the *effectiveness* of an intervention, which focuses on the "degree of beneficial effect under 'real world' clinical settings" (Gartlehner et al., 2006: p. 3). For the ASD context, this "real world" setting invariably involves home-based interventions and substantial parental involvement (Schertz, Baker, Hurwitz, & Benner, 2011). Arguably then, as the child-parent relationship is bi-directional, parents should not be excluded from assessing intervention outcomes, especially as parental assessments may have greater ecological validity. The efficacy vs. effectiveness distinction mirrors the well-known 'statistical significance vs. clinical significance' divide in medical outcomes research. While the efficacy approach maximises internal validity, the effectiveness approach maximises generalizability (i.e., external validity).

To date behavioural approaches characterised by intensive interventions delivered for up to 40 h per week for a minimum of two years, have the strongest empirical support from clinical studies (e.g., Klintwall, Eldevik, & Eikeseth, 2015). For example, intensive applied behavioural analysis (iABA) approaches utilising discrete trials methods have been found to be efficacious with adaptive and challenging behaviours, and intellectual and language skills (Caron et al., 2017). Less intensive behavioural therapies also centring on behavioural modification techniques have been shown to reduce tantrums and self-injurious or disruptive behaviours (Schell & Adams, 1971). Intervention studies involving speech therapies have been mixed, for example, while Picture Exchange Communication Systems and video-modelling are linked to improvements in communication, social interaction, and cooperative play (Lerna, Esposito, Conson, & Massagli, 2014; Wang, Cui, & Parrila, 2011), other methods such as social stories have been less well supported (Samuels, 2011; Reynhout & Carter, 2010). Likewise, occupational therapies, which predominantly target social or work skills, motor or sensory difficulties, and play (Welch & Polatajko, 2016) have support from some studies (e.g., Dunn, Cox, Foster, Mische-Lawson, & Tanquary, 2012; Kientz & Dunn, 2012) but not others (Tanner, Hand, O'Toole, & Lane, 2015). Finally, the impact of complementary and alternative interventions such as gluten- and/or casein- free diets, and dietary supplementation, have proven difficult to evaluate due to a lack of quality research (Millward, Ferriter, Calver, & Connell-Jones, 2014; Mari-Bauset, Zazpe, Mari-Sanchis, Llopis-Gonzales, & Morales-Suarez-Varela, 2014).

Few studies have focused on parent experiences of the interventions their child engages (e.g., Hume, Bellini, & Pratt, 2005; Boyd & Corley, 2001). One study involving iABA interventions found that the majority of parents reported general satisfaction or high satisfaction with the improvements in their child's behaviour (Boyd & Corley, 2001). Other studies also support the notion that iABA is perceived as effective by parents (Bowker, D'Angelo, Hicks, & Wells, 2011; Runco & Schreibman, 1983). Using an internet-based survey, Goin-Kochel and colleagues (2009) examined parent's (n = 479) "efficacy" ratings of their child's ASD-related Interventions, including speech language therapy, occupational therapy, iABA, and dietary interventions. They reported mixed results both across and within intervention types, and noted that there were substantial numbers of parents indicating that these interventions dramatically or somewhat improved their child's core symptoms. Interestingly, these improvements were reported even for interventions lacking an evidence-base, for example, dietary interventions were reported by parents to be particularly effective in improving social behaviours. However, parental assessments of child intervention outcomes may be influenced by their expectations, and subsequently how they report that their expectations have, or have not, been met. While parental expectations of intervention outcomes ('outcome expectancy') and their ability to effectively contribute to the intervention ('efficacy expectations') have been associated with actual intervention outcome (Ivy, 2004), little research dedicated to parental expectations has been published.

A number of studies have reported discrepancies between parental assessments and statistically significant improvements reported from clinical intervention studies. Using a dietary example, Pennesi and Cousino Klein (2012) reported no statistically significant improvements in communication deficits and behavioural problems, even though the children's parents did. Similarly, exploring the effect of a classroom-based language invention, Adams et al. (2012) reported no significant advances in speech or narrative ability, yet both parent and teacher measures indicated significant improvements. Likewise, Elder et al. (2006) reported non-significant effects on problem behaviours with a dietary intervention, nevertheless parents reported improvement in their child's language and a reduction in hyperactivity and tantrums. Hutchins & Prelock (2013, 2016); reported conflicting findings between objective clinical measures and subjective parental assessments when evaluating the impact of social stories on children. What these

studies demonstrate is the importance of validating interventions beyond the clinical environment, as statistical findings based on clinical outcome measures may not correspond with the real-life experiences of the parents and their child.

Parental stress can impact children's well-being, and increase their risk of being abused or neglected (Whitmore, 2016), all serving to counteract the effectiveness of interventions (Osborne, McHugh, Saunders, & Reed, 2007). Research generally focuses on caregiving stress levels and the efficacy of various interventions independently, and very few studies have explored the effects of intervention engagement on parental stress levels (Bendixen et al., 2011). Furthermore, parents typically engage their child with multiple interventions at any one time, with the resultant increases in time and monetary demands associated with higher parental stress (Mackintosh, Goin-Kochel, & Myers, 2012). While some research into behavioural interventions have reported decreases in parenting stress (e.g., Smith, Buch, & Gamby, 2000) or stability in stress scores (Remington et al., 2007) following behavioural Interventions, there is a paucity of research into other therapeutic modes.

Understanding parents' assessments of interventions is important, giving that clinical efficacy may not readily translate into real-world gains for the child, especially if factors such as parenting stress serve to attenuate any positive effects associated with the intervention. Furthermore, as arbiters of their child's Interventions, parental assessments of effectiveness are critical as any intervention judged ineffective will likely be discontinued, even if the clinician or practitioner disagrees (Bowker et al., 2011). Additionally, some studies have reported extensive communication of ASD-related service experiences among parents of a child with ASD (Pickard & Ingersoll, 2014). Negative intervention experiences could therefore result in other parents being discouraged from pursuing that intervention. This is concerning as a negative experience may not necessarily be caused by the intervention itself, but rather the professionals performing the intervention (Mackintosh et al., 2012). Studies have indicated that parent-therapist rapport is a vital prerequisite of positive parent effectiveness judgments (Carlon, Carter, & Stephenson, 2013). Additionally, due to the broad nature and presentation of ASD, it cannot be assumed that what works (or does not) for one child will work (or not) for another (Sherer & Schreibman, 2005).

While traditionally it has been left to clinicians to describe a child's symptom profile, it is likely that their assessments may depend more heavily on parental reports than rigorous clinician observation, and arguably the gap between clinician and parental assessments may be overstated (Miller et al., 2017). At the very least, parental assessments are an important adjunct source of information on intervention effectiveness (Goin-Kochel, Myers & Macintosh, 2009). The present study focuses on parental assessments of their child's exposure to one-or-more of the mainstream ASD interventions commonly found in the New Zealand context, specifically speech language therapy, behavioural therapy, iABA, occupational therapy, and dietary interventions. These five mainstream interventions were assessed by parents in terms of treatment effectiveness with reference to a primary target symptom. This parental focus is fundamentally important as parents often play a central role in the intervention process and a paucity of research exists relating to parental assessments of treatment effectiveness. In relation to the current gaps in the literature, Karst and Van Hecke (2013) declare "At this time, however, simply knowing more about how various ASD treatments impact parents and families is of primary necessity" (p. 268). To this end, parents in the current study were also asked the degree to which the intervention impacted on parenting stress, as parental stress levels may serve to modify the effectiveness of their child's interventions. We also asked parents about their expectations prior to engaging an intervention, and determined whether those expectations had, or had not been, met.

2. Methods

2.1. Participants

Participants consisted of 585 parents of a child formally diagnosed (i.e., paediatrician or psychologist) with ASD. Mothers made up the majority of respondents ($n = 529$, 91%), while the majority of the children with ASD were reported to be male ($n = 482$, 82%). At the time of survey completion, the average age of the parent sample was 44.9 years ($SD = 7.76$, min = 19, max = 62), while the average age of the children with ASD was 12.02 years ($SD = 5.85$, min = 2, max = 19). Approximately 37% of children ($n = 168$) possessed other medical or psychological conditions, with anxiety disorder ($n = 104$), ADHD ($n = 78$), and Global Developmental Delay/Intellectual Disability ($n = 65$) being the most common. Of the entire sample, 47 parents (8%) reported that their child had never received treatment of any sort, and so were excluded from analyses. Ethics approval was given by the Auckland University of Technology's Human Ethics Committee (AUTEC: 13/105).

2.2. Materials

Intervention engagement and perceived effectiveness Five mainstay interventions summarise the New Zealand autism treatment context (Shepherd, Landon, & Goedeke, 2017): behavioural therapies (BT); intensive Applied Behavioural Analysis (iABA) approaches; speech language therapy (SLT); occupational therapy (OT); and dietary interventions (DI). When considering the involvement of a child in any of these Interventions, four groups can be derived to represent 'intervention history'. First, if the child has not been exposed to the characteristic components that make up an intervention modality, then the intervention can be classed as 'untried'. Second, if the child is currently participating in the intervention, it can be classified as 'ongoing'. Third, if a child has engaged and then terminated an intervention prior to the realisation of therapeutic goals, then the intervention is said to have been 'abandoned'. Lastly, if the intervention terminates coincidentally with the realisation of therapeutic goals, then the intervention has been 'completed'. Parents were serially presented descriptions of the five mainstream interventions (i.e., iABA, BT, DI, OT and SLT) and asked if, either in the past-or-present, their child had received interventions of that type. Following a "Yes" response, a series of questions relevant the intervention were presented, beginning with items probing age (in years) that their child began the

intervention, and if the intervention was still being engaged (i.e., "Ongoing"). If the intervention had been stopped, then the age of termination was probed along with the reason why the intervention was terminated. Here, a number of fixed options were presented: *too expensive to continue*; *I don't think it was working*; *Became unavailable*; *The time pressure is too great*; *I deemed it too risky*; *We achieved what we set out to achieve*. If parents selected "We achieved what we set out to achieve" then that intervention was determined to be "Completed", while for all other options the intervention was considered to be abandoned.

Next, parents were asked to identify the symptom the intervention was primarily attempting to address from the following options: Communication/Language (e.g. spoken language, conversations with others, gestures etc.); Restrictive Interests and Behaviours (e.g. insistence to sameness, repetitive body movements and behaviour, resistant to change etc); Odd/Atypical Behaviour (e.g. repetitive movements, flaps hands etc); Social Interaction (e.g. peer relationships, participation in social activities etc); Sleep disturbance; Sensory Issues; Eating Difficulties; Toileting; Motor difficulties. Additionally, an open-ended option was provided: Other (please specify). Parents were then asked, in relation to the target symptom, what their expectations of the intervention had been prior to its start, as-well-as how effective they judged the intervention to have been in practice. Both these items were rated on a seven-point Likert-type scale ranging from 1 (*No Improvement*) to 7 (*Substantial Improvement*). Additionally, parents were asked how helpful the intervention was in terms of relieving their own parenting stress using a seven-point scale ranging from 1 (*Not Helpful*) to 7 (*Very Helpful*).

2.3. Procedure

Data were collected online via an internet-based survey developed specifically for this study. Parents were recruited using advertisements distributed in August 2016 by New Zealand's largest national autism association, Autism New Zealand. On accessing the survey, parents were presented with a participant information sheet and made aware that a completed survey indicated their consent to partake in the study. Parents then answered questions about themselves (e.g., age, gender, education) and their child (e.g., age, gender, comorbidities) before completing the ASD task-related stress inventories. Questions about their child's intervention history followed, and the survey concluded with an open-ended question asking parents for any final comments regarding their experiences of parenting a child with ASD.

2.4. Analysis

All statistical analyses were performed using the Statistical Package for the Social Sciences (v.22). For all tests, the significance level was set at $\alpha = .05$, except in the case of *post hoc* analyses, in which the alpha value was adjusted according to the Bonferroni criterion. One way analyses of covariance (ANCOVA) were performed to compare group means while controlling for parent age and education, and child age. Parent age controlled for the 'wear-and-tear hypothesis', where studies have found that mothers of older children with ASD tend to have higher exhaustion levels or maladaptive emotions than mothers of younger children with ASD (e.g., Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008), or, on the other hand, that the coping skills of ASD parents may improve over time (Gray, 2003). Child age was included as children with ASD tend to exhibit improvements as they grow (Shattuck et al., 2007). Parent education was used as an indirect measure for socio-economic status.

To represent a child's intervention history, each intervention was coded as *ongoing*, *abandoned* or *completed*, as appropriate. One-way ANCOVA's were performed to examine if mean ratings for three dependent variables of interest (i.e., expectations of Interventions, evaluations of Interventions, and how these interventions relieved stress), differed between the five interventions. To further refine the analysis, ANCOVAs were performed to determine if differences in the dependent variables (i.e., expectations, parent-rated effectiveness and helpfulness with stress) could be attributed to intervention history (i.e., ongoing, abandoned, completed). To assess whether parent expectations had been met, effectiveness ratings were subtracted from reported expectations to produce a difference score. Here, a score of zero implies that expectations had been met, a positive value that expectations had been exceeded, and negative values that expectations had not been met. Mean difference scores were subjected to a single-sample *t*-test with the test statistic set to zero. Finally, parent-rated effectiveness and helpfulness with stress ratings were tabulated across the five modalities according to the symptom classified as the primary target. Because substantial variations in groups sizes across both intervention and target symptoms were evident, inferential testing was not undertaken.

3. Results

3.1. Intervention completion rates

Table 1 indicates the number of parents who have engaged their child in each of the five interventions (All), and of those the number of children who are still engaged (ongoing), who had terminated the intervention (abandoned) or who had satisfactorily completed the intervention (completed). Considering only the percentage of children who are no longer engaged in the intervention it is possible to calculate percentage completions, where the complement represents percentage abandoned. Using the data from Table 1, the completion rates are as follows: SLT (28.6%), BT (19.1%), iABA (12.5%), OT (20.2%) and DI (18.5%).

3.2. Intervention effectiveness

Parents rated intervention effectiveness on a five-point scale with reference to a target symptom. Table 1 presents mean

Table 1

Parent-ratings of their expectations and experiences of intervention effectiveness relative to a target symptom, and how the intervention helped relieve their parenting stress. Mean scores are categorised according to intervention history (i.e., ongoing, abandoned, and completed). For outcome measures, parentheses contain standard deviations, asterisks indicate if the difference scores calculated between mean Effectiveness and Expectations ratings are significantly different from zero. The superscript letters flag significant statistical relationships within a single intervention and single outcome variable.

	n	Expectations	Effectiveness	Difference Score	Stress Reduction
SLT: All	385 (66%)	3.62 (1.0)	2.83 (1.3)	−0.82*** (1.5)	2.73 (1.4)
a. Ongoing	129 (34%)	3.69 (1.1)	2.84 (1.2)[c]	−0.84*** (1.5)	2.96 (1.3)[b]
b. abandoned	182 (47%)	3.52 (1.0)	2.43 (1.2)[c]	−1.14*** (1.4)	2.31 (1.3)[a,c]
c. Completed	73 (19%)	3.74 (0.9)	3.77 (0.9)[a,b]	0.04 (1.04)	3.41 (1.2)[b]
BT: All	285 (49%)	3.57 (1.0)	2.79 (1.2)	−0.76*** (1.4)	2.86 (1.3)
a. Ongoing	85 (30%)	3.46 (0.9)	2.87 (1.2)[c]	−0.56** (1.4)	3.01 (1.3)[b]
b. abandoned	161 (56%)	3.63 (1.0)	2.51 (1.2)[c]	−1.11*** (1.4)	2.54 (1.2)[a,c]
c. Completed	38 (13%)	3.53 (0.9)	3.78 (1.0)[a,b]	0.27 (1.3)	3.82 (1.1)[b]
iABA: All	78 (13%)	3.84 (1.0)	3.26 (1.4)	−0.62** (1.5)	3.34 (1.5)
a. Ongoing	22 (28%)	3.73 (1.0)	4.05 (1.1)	0.29 (1.3)	4.18 (1.1)
b. abandoned	49 (63%)	3.82 (0.9)	2.78 (1.4)	−1.07*** (1.5)	2.81 (1.5)
c. Completed	7 (9%)	4.29 (1.1)	4.17 (0.8)	−0.50 (1.0)	3.86 (1.3)
OT: All	370 (63%)	3.39 (1.0)	2.8 (1.1)	−0.59*** (1.5)	2.8 (1.2)
a. Ongoing	114 (31%)	3.37 (0.9)	2.97 (1.0)[c]	−0.39** (1.2)	3.00 (1.2)[b,c]
b. abandoned	202 (55%)	3.41 (1.0)	2.47 (1.1)[c]	−0.94*** (1.5)	2.49 (1.3)[a,c]
c. Completed	51 (14%)	3.38 (1.)	3.68 (0.9)[a,b]	0.30 (1.3)	3.53 (1.1)[a,b]
DI: All	234 (40%)	3.24 (1.1)	2.84 (1.5)	−0.42** (1.7)	2.67 (1.4)
a. Engaged	101 (43%)	3.36 (1.1)	3.61 (1.3)[b]	0.25 (1.7)	3.41 (1.3)[b]
b. abandoned	106 (45%)	3.10 (1.2)	1.89 (1.2)[a,c]	−1.22*** (1.5)	1.81 (1.1)[a,c]
c. Completed	24 (10%)	3.41 (1.1)	3.83 (0.9)[b]	0.41 (1.4)	3.33 (1.3)[b]

Note. $* \ p < .05, ** \ p < .01, *** \ p < .001.$

effectiveness ratings across intervention history: those whose child had engaged the intervention in the past or present (all), only those whose child is currently engaging the intervention (ongoing), and those whose child engaged the intervention in the past and either aborted (abandoned) or completed (completed) the intervention. Comparing mean effectiveness ratings across the interventions (i.e., Table 1: All), a one-way ANCOVA ($F(4, 1275) = 2.703$, $p = .029$, $\eta_p^2 = 0.092$) indicated significant differences across the five intervention types. Subsequent *post hoc* tests revealed that the mean effectiveness rating for iABA was greater than the means for the other four interventions.

Next, comparisons across intervention histories, but within a single intervention, revealed that for SLT ($F(2, 355) = 21.387$, $p < .001$, $\eta_p^2 = 0.108$), BT ($F(2, 258) = 9.349$, $p < .001$, $\eta_p^2 = 0.068$) and OT ($F(2, 258) = 23.449$, $p < .001$, $\eta_p^2 = 0.121$), those whose child had completed the invention rated it higher than those with a child currently engaged or who had been withdrawn. Additionally, for OT, those parents whose child had abandoned the intervention had lower mean effective ratings than those with children currently receiving OT. Finally, for DI, those whose child had been withdrawn from this approach had lower mean effectiveness ratings than those with children currently engaged or who had completed ($F(2, 206) = 36.083$, $p < .001$, $\eta_p^2 = 0.259$).

3.3. Intervention expectations

Using a five-point scale parents were asked to rate their expectations of the interventions that they had engaged with their child. To determine if mean expectations differed across the five Interventions, a one-way ANCOVA was conducted and found to be significant ($F(4, 1321) = 27.171$, $p < .001$, $\eta_p^2 = 0.287$). *Post Hoc* tests indicated that parent expectations towards iABA therapy were significantly higher than all of the other four Interventions, while those towards DI were significantly lower than the other four interventions. A battery of five ANCOVA's revealed that, for each of the five interventions in turn, there were no significant differences in mean intervention expectations across intervention history (i.e., ongoing *vs.* abandoned *vs.* completed). By subtracting expectation scores from the ratings of actual effectiveness, a difference score was derived indicating whether expectations were met (≈ 0), were not met (negative values) or were exceeded (positive values). Table 1 lists these difference values for the five mainstream interventions. With the test value set to zero, one-sample *t*-tests were performed to determine if each difference score differed significantly from zero. From Table 1 it is evident that those who completed the interventions indicated that their expectations had been met, while for those withdrawing their child from the intervention the opposite was true. Furthermore, for those indicating that their child is currently engaging an intervention, expectations also appear not be met, except for iABA. Note that no positive values were significantly different from zero, indicating that on average the expectations of parents are not being exceeded.

3.4. Intervention impact on parenting stress

Ratings of whether an intervention helped reduce parenting stress are displayed in the final column of Table 1. Comparing data from the entire sample (i.e., all) across all five Interventions, a significant ANCOVA model was obtained ($F(4, 1275) = 3.818$, $p = .004$, $\eta_p^2 = 0.110$). Bonferonni-adjusted *post hoc* tests revealed that the greatest mean impact on parenting stress was obtained from the iABA intervention, which returned a mean helpfulness score significantly higher than any of the other four interventions.

Table 2

Mean parent-rated intervention effectiveness scores categorised according to target symptom for five ASD interventions. Parentheses contain frequencies, while a weighted mean (final column) represents mean effectiveness ratings for each symptom without respect to intervention type.

Target Symptom	SLT	BT	iABA	OT	DI	Mean
Language (n = 375)	2.89 (282)	3.00 (22)	3.48 (33)	3.00 (16)	2.18 (22)	2.91
Behaviour (n = 107)	2.40 (5)	2.95 (41)	3.00 (9)	2.53 (32)	2.65 (20)	2.75
Odd Behaviour (n = 26)	3.00 (3)	2.56 (9)	N/A (0)	2.83 (6)	4.00 (8)	3.12
Social Deficits (n = 192)	2.50 (32)	2.59 (86)	3.50 (10)	2.51 (50)	2.28 (14)	2.56
Sleep (n = 16)	3.50 (2)	3.50 (4)	N/A (0)	1.67 (3)	3.00 (7)	2.94
Sensory Issues (n = 127)	2.50 (6)	3.22 (23)	N/A (0)	3.01 (88)	2.70 (10)	2.99
Eating (n = 59)	3.00 (4)	N/A (0)	N/A (0)	2.56 (9)	2.55 (46)	2.58
Toileting (n = 40)	N/A (1)	3.00 (8)	N/A (1)	3.06 (16)	3.25 (16)	3.12
Motor Deficits (n = 95)	2.67 (3)	4.33 (3)	N/A (1)	2.85 (87)	3.50 (2)	2.90
Other (n = 252)	2.63 (30)	2.71 (83)	3.43 (14)	2.73 (44)	3.11 (81)	2.87

Note. SLT Speech Language Therapy; *BT* Behavioural Therapy; *iABA* Applied Behavioural Analysis; *OT* Occupational Therapy; *DI* Dietary Interventions.

When considering experience within a specific intervention, differences in mean scores were noted for all but the iABA intervention ($F(2, 58) = 2.329$, $p = .107$, $\eta_p^2 = .074$). For SLT ($F(2, 355) = 14.504$, $p < .001$, $\eta_p^2 = 0.076$), BT ($F(2, 264) = 6.954$, $p = .002$, $\eta_p^2 = 0.051$), and DI ($F(2, 207) = 33.066$, $p < .001$, $\eta_p^2 = .242$). Parents whose child failed to complete the interventions reported mean lower help with stress scores than those whose child had either completed or were still engaging the intervention. Finally, for OT, ($F(2, 333) = 14.352$, $p < .001$, $\eta_p^2 = 0.079$), all three pairwise comparisons were significantly different.

With reference to Table 1, reduction of stress appears strongly coupled to intervention effectiveness ratings. Partial correlation coefficients, controlling for parent and child age, and parent education, between intervention effectiveness and related stress reduction reveal a close coupling between the two measures. Strong, positive correlations were noted for all five intervention modalities: SLT ($r = .746$, $p < .001$), BT ($r = 0.744$, $p < .001$), iABA ($r = .791$, $p < .001$), OT ($r = .763$, p k $< .001$) and DI ($r = 0.824$, $p < .001$).

3.5. Target trait, intervention effectiveness and help with stress

Mean parent-rated effectiveness scores are provided in Table 2 for the symptom primarily addressed by the intervention. On this scale, a score of '1' indicated no improvement in the symptoms being targeted, a '3' moderate improvement, and a '5' substantial improvement. Visual inspection of Table 2 indicates that, on average, effectiveness scores clustered around the middle of the scale, suggesting some improvement had been noted, but that the improvement was not substantial. When interpreting these mean values, attention should be directed toward the number of children receiving a particular intervention (parentheses, Table 2), as for some symptoms these numbers can be low. When examining an intervention's most targeted symptom, mean effectiveness ratings ranged from 2.55 (DI, *eating*) to 3.48 (iABA, *language*), indicating that, on average, therapeutic gains are being reported by parents. Without respect to intervention modality (Table 2: final column), odd behaviours (e.g., hand flapping, odd approach to people) and toileting are the symptoms parents assess as most successfully treated, and social deficits and eating difficulties the least.

For completeness, the parent-ratings of how useful the interventions were in terms of relieving their stress are presented in Table 3. Without respect to intervention type (Table 3: final column), treatments targeting sleep or sensory issues are associated with the highest reports of stress reduction, while those targeting odd behaviours or social deficits are linked to the least.

4. Discussion

The findings obtained in this study add to the limited literature addressing parental assessments of the interventions engaged by

Table 3

Mean parent-rated stress-relief following intervention engagement categorised according to target trait for five ASD interventions.

Target Symptom	SLT	BT	iABA	OT	DI	Mean
Language (n = 375)	2.78	3.41	3.52	2.88	2.45	2.87
Behaviour (n = 107)	2.20	3.07	3.22	2.50	2.40	2.75
Odd Behaviour (n = 26)	2.67	2.22	N/A	2.50	2.88	2.54
Social Deficits (n = 192)	2.28	2.65	3.40	2.68	1.93	2.58
Sleep (n = 16)	3.50	4.00	N/A	2.67	3.00	3.25
Sensory Issues (n = 127)	3.17	2.91	N/A	2.99	2.40	2.94
Eating (n = 59)	3.00	N/A	N/A	2.78	2.67	2.71
Toileting (n = 40)	N/A	3.00	N/A	3.00	2.75	2.90
Motor Deficits (n = 95)	2.33	2.33	N/A	2.75	3.00	2.73
Other (n = 252)	2.90	2.87	3.36	2.84	2.85	2.89

Note. SLT Speech Language Therapy; *BT* Behavioural Therapy; *iABA* Applied Behavioural Analysis; *OT* Occupational Therapy; *DI* Dietary Interventions.

their child with ASD. The first finding indicates that, in terms of intervention success, a higher number of parents report intervention disengagement relative to those reporting satisfactory completion. The highest completion rate was for SLT, where approximately one-in-four parents whose child had engaged SLT in the past considered the target symptom to have been sufficiently treated. The lowest reports of intervention completion were for iABA, with approximately 12% of parents indicating that their child's intervention had ceased due to the realisation of therapeutic goals. This proportion is similar to that reported by Bowker et al. (2011), who indicated that only four (≈12%) parents in their study (n = 34) reported that iABA intervention had ceased because intervention goals had been reached. Our finding needs to be interpreted with due consideration, however, as far from reflecting intervention effectiveness, other factors may offer more plausible explanations. It may be, for example, that language problems may be more effectively treated than behavioural problems. However, our data suggest that most individuals engaging either SLT or iABA do so to treat language dysfunction, and so it is unlikely that differences between the target symptoms can account for the differences between SLT and iABA completion rates. Furthermore, this finding is at odds with the parent's ratings of iABA Therapy, which was significantly higher than the other four modalities. Instead, this difference may be a contextual effect explained by the lack of funding in New Zealand for iABA Therapy, with parents enrolling and then withdrawing their child as the financial burden cumulates (Shepherd, Csako, Landon, Goedeke, & Ty, 2018).

Currently, there are few pre-existing reports on parent-reported intervention completion rates to use as a comparison. Data from Goin-Kochel, Mackintosh, & Myers, 2009 indicate that approximately 20% of parents reported that iABA Therapy was ineffective, though their definition of iABA was broad and would have certainly included approaches that we classified as BT. Further, they reported that 28% and 26% of parents rated SLT and OT poorly, respectively. However, they did not indicate at what stage of the intervention cycle the children were in at the time their parents made their ratings. Irrespective of cause, however, our data indicate that completion rates across the five intervention modalities are low. This may reflect two underlying causes, the first being that while ASD is treatable it is not curable. Thus, when making their responses parents may consider a successful intervention as one which eliminates the target symptoms. Decades of ASD research confirm that the core symptoms of ASD are chronic (Volmar & Pauls, 2003), and while so called cases of 'optimal outcome' are reported (Fein et al., 2013), it is unlikely that any intervention or combination of interventions will emerge as a panacea to take individuals with ASD into a 'neurotypical' category. Second, while some interventions are effective for some children on the spectrum, they may not be effective for others. Faced with limited intervention options, parents may simply adopt a "try and see" approach (Bowker et al., 2011) irrespective of whether there is evidence that the intervention is effective for the target symptom. Consequently, when the interventions fail to reduce or eliminate symptoms, parents may negatively assess the intervention and withdraw their child.

The finding that parents who engaged iABA therapy rated it as the most effective (relative to a target symptom) is consistent with the empirical evidence reported in the literature (Regehr & Feldman, 2009), and with a previous study using a smaller New Zealand sample (Shepherd et al., 2017). Regehr and Feldman (2009) reported that parents felt the most engaged when their child underwent iABA Therapy compared to other Interventions, which subsequently influenced their effectiveness ratings. Our findings serve to replicate the data reported by Goin-Kochel et al. (2009). They noted that, of the 225 parents in their sample whose child had engaged ABA Therapy, 77% reported that symptoms improved 'dramatically' or 'somewhat'. However, while Goin-Kochel et al. (2009) report generally positive assessments from parents, we note that the mean iABA effectiveness rating made on the current study's five-point scale was decidedly moderate (M = 3.26). Again, this may indicate the fact that ASD is incurable, and that interventions may not typically be effective to address core symptoms in general. This in turn may incline parents to avoid higher ratings. Lastly, it may simply be that the intensive nature of iABA is producing greater therapeutic outcomes, and it remains to be seen what the outcome would be if other modalities were more intensive (e.g., 40 h a week).

Parent ratings across all five intervention modalities used in the current study indicated that, on average, interventions were assessed by parents to be moderately effective only. In comparison, Goin-Kochel et al. (2009) reported that, to varying degrees, most parents in their sample reported improvements while their child underwent SLT (72%), OT (72%), and DI (45%). More direct comparisons can be made when their categories (re: their Tables 2 and 3) are reverse coded (1 = Child became worse, 2 = no noticeable effect, 3 = improved somewhat, 4 = improved dramatically), while our data are collapsed from a five to four-point scale. This done, our mean effectiveness scores begin to look more similar to theirs, tending to the middle of scale (i.e., ≈ 2.5) with a slight bias towards positive assessment: SLT (2.42 vs. 2.97), iABA (2.70 vs. 3.08) OT (2.35 vs. 2.93) and DI (2.38 vs. 2.81). The consistently higher means of Goin-Kochel et al. (2009) may be explained by the makeup of their sample being predominantly (92%) North American. In contrast to New Zealand's publicly-funded health system, American healthcare is biased towards a 'user pays' approach, and as Karst and Van Hecke (2013) point out, consumers may be biased towards more positive assessments of their child's intervention when they have invested money into it.

Parent-rated effectiveness scores can also be examined according to where their child currently resides in the intervention process (i.e., ongoing, abandoned, completed). In the current study, differences in effectiveness ratings across intervention history were noted for all but the iABA modality. For iABA Therapy, effectiveness ratings were not significantly different across the three categories, though this finding is likely explained away as a statistical artefact emerging from inadequate samples sizes across the three groups, particularly the completers. Predictably, for SLT, BT, and OT, those whose child completed an intervention judged it as more effective than those currently undertaking it or who had abandoned it. Further, in terms of parent effectiveness ratings, there were no differences between those whose child was currently engaged and those whose child had abandoned the interventions. For DI, parent ratings for children who had been withdrawn from this approach were on average lower than those with children currently engaged or who had completed. From these data, we can conclude that when asking parents to rate the effectiveness of their child's intervention it is important to note where on the intervention timeline their child is, otherwise effectiveness ratings could be biased up-or-down and be unrepresentative.

Mirroring the effectiveness data, parents with a child undergoing iABA reported greater mean stress reduction directly attributable to the intervention compared to the other four modalities. This is an interesting finding, as given the intensive nature of iABA Therapy it might be expected to increase parental reports of intervention-related stress. A common assumption is that interventions reducing child problem-behaviour also improve parental wellbeing. On the other hand, it might be argued that, given the time and financial demands that intervention engagement places on parents, an increase in stress may be expected irrespective of intervention gains (Karst & Heck, 2012). Alternatively, with effectiveness-ratings coming from the parents themselves, stress induced by participating in their child's interventions might blind them to positive treatment gains (Kazdin & Weisz, 1998). Our data indicated a positive correlation between parent-rated intervention scores and how the intervention impacted their stress. Thus, it appears that, irrespective of intervention demands, any reduction in child symptoms is linked to a reduction of parent stress. Future studies are required, however, to determine the relative contributions of intervention engagement and change in child symptoms to subsequent parenting stress levels.

Parental expectations of interventions (i.e., 'outcome expectancy') have been associated with intervention outcomes in the long term (Field & Hoffman, 1999), to such a degree that some have warned of placebo effects when using effectiveness ratings from parents with of child with ASD (Coplan et al., 2003). Expectations may be raised in parents by exposure to scientific literature, parent beliefs that intervention cost is related to intervention effectiveness (Goin-Kochel et al.. 2009), or else unscrupulous service providers promising parents complete cures (Grindle, Kovshoff, Hastings, & Remington, 2009). Interesting, in the current study we found that parents engaging in iABA Therapy, the most empirically supported of all ASD Interventions, had significantly higher expectations than the remaining four interventions. This maybe be explained either by parents being exposed to the findings of scientific studies, or that the aforementioned high costs of iABA Therapy in New Zealand serve to increase expectations relative to the government-funded (i.e., SLT, BT, iABA) options. However, for DI, parent expectations were significantly lower than the other four Interventions, even though DI is not typically funded in New Zealand and the costs fall on the parents. Taken together, these two findings indicate that intervention cost may not be driving expectations, but given that many dietary approaches are not evidence-based (Regehr & Feldman, 2009), it may be that expectations are coupled to efficacy information obtained by the parents. However, some report that when making intervention choices, parents are more likely to use "gut feeling" or "intuition" rather than research evidence (Carlon, Carter, & Stephenson, 2015). Clearly then, more research is required to uncover the influences on parental expectations, independently of their intervention choices.

An indirect measure of expectation outcome was obtained by creating a difference score between expectations and effectiveness ratings. For all five intervention modalities we found that, on average, parents reported that expectations had not been met. However, when intervention history was considered, those reporting that their child's intervention had concluded satisfactorily (i.e., completers) indicated that on average they felt their expectations had been met. However, on aggregate, parents did not report that their intervention expectations had been exceeded, irrespective of intervention history. As anticipated, for those parents abandoning their child's intervention, expectations were significantly higher than their effectiveness ratings, indicating that expectations had not been met. For parents reporting that their child is currently engaging Interventions, only for iABA and DI were there reports that expectations were being met, while for the three government-funded interventions the opposite was true. Interestingly, intervention history does not appear to affect expectancy scores, suggesting that intervention experiences *per se* have not biased the parents' retrospective ratings.

Parent expectations of intervention effectiveness are also coupled to the types of interventions they choose for their child, especially in terms of the specific ASD symptoms that they wish to address (Grindle et al., 2009). Goin-Kochel et al. (2009) emphasise the importance of moving beyond the four core symptoms of ASD when asking parents to assess the effects of interventions upon their child, and so we also asked parents to identify the primary symptoms or areas of functioning being targeted. Our data show that language impairments and social deficits are the top two symptoms being targeted during Interventions, and what-is-more, the pattern of intervention uptake appears to depend on the symptom. For example, 77% percent of those children engaged in SLT were treated for specific language deficits, compared to 5% of those engaged in OT. While it was not possible to compare effectiveness ratings across intervention type due to large disparities in sample size, it is noted that parent-ratings are again highest for iABA Therapy. For the two most commonly targeted symptoms, parents considered interventions for the child's language deficits to be on average moderately effective, while social deficits were judged as the least effectively treated (see Table 2). Further, interventions targeting social deficits were also reported to have the least positive impact on parenting stress. Without respect to intervention mode, odd behaviours and toileting were considered the most successfully treated symptoms by parents. Thus our findings partly mirror those reported by Bowker et al. (2011), who reported that parents perceived language and behavioural function as the areas most improved by therapy, and that social functioning was the area of their child's functioning that was least improved by therapy.

4.1. Limitations

Survey-based designs invariably involve a number of factors limiting the interpretation of the results. First, parent ratings of intervention effectiveness are by their nature subjective, and ratings may be affected by confounding factors such as parent age, coping ability or parenting self-esteem. However, it could be argued that many clinical assessments of children with ASD depend on parental reports as opposed to substantial periods of clinical observation, even during efficacy trials. Second, children are often exposed to multiple treatments, up to seven concurrently (Green et al., 2006). Disentangling the effects of different concurrent interventions is therefore a challenge (Goin-Kochel, Myers, & Mackintosh, 2006), but in this study is partly mitigated by asking parents to rate the specific symptoms that each intervention targeted. As active participants in their child's Interventions, parents would be best placed to judge the degree that each treatment was/is impacting their child's functioning (Bowker et al., 2011; Goin-

Kochel et al. (2009)). Third, the representativeness of the sample cannot be assessed given the recruitment method, though the sample size can be considered large for a study of this type. Lastly, the very nature of retrospective ratings invites potential confounding factors, including impaired memory recall.

4.2. Implications

In the current study, and only a handful of others (e.g., Goin-Kochel et al., 2009), parents rather than clinicians were asked to assess every-day interventions. Parental assessments of intervention effectiveness, measured in terms of both their child's improvements as-well-as their own parenting stress levels, are important given the systematic nature of ASD Interventions, which typically occur not only in the clinic, but also in the home and school environments. In this respect an inclusive approach to child assessment should be embraced, even in the context of clinical trials, where parental assessments could add incremental validity. In this study we show that the Autism Impact Measure (AIM) scale may be a valid tool for parents to assess the impact of interventions on particular domains of functioning pre- and post-treatment. However, when considering parental ratings it must be acknowledged that not only are the strict protocols of the clinical trial absent, but that parents may enrol their child into interventions that are not necessarily a good match for their child's constellation of symptoms. Consequently, more research is required to determine the child symptom profiles that predict positive responses to Interventions, to ensure that the child is receiving the best of care.

It is not sufficient to evaluate interventions in only clinical environments with clinical outcome measures, where even positive outcomes may trigger negative effects on the family system (Lord & Bishop, 2010). ASD-related dysfunction is contextual, and given that children spend most of their time with their family, parental measures may offer additional insights into intervention effectiveness (Murray et al., 2009). Pertinently, the parent-child relationship is bi-directional, and increased parental stress, including stress caused from participating in intensive intervention regimes, may counteract the positive impacts of interventions. Our findings indicate a positive correlation between parental assessments of their child's interventions and how their stress changed as a result. Future studies are needed to examine if factors such as coping and resilience moderate the relationship between intervention effectiveness and parent reports of stress reduction. Further understanding of this relationship may in future lead to programmes better able to support parents of a child with ASD.

Conflicts of interest

All authors declare that they have no potential or competing conflicts of interest.

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