



A Case-Series Investigation of an Integrated Parent-Mediated Intervention for Childhood Autism: ParentWorks-Spectrum

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Abstract

Background: Children with autism spectrum disorder (ASD) and their families often experience difficulties that extend beyond the social communication difficulties and repetitive patterns of behaviour and interests that are core to the disorder. Parent mediated interventions for ASD have received considerable support yet are often lengthy and rarely address additional areas of need. This study investigated the feasibility, acceptability, preliminary effectiveness of a novel parent mediated intervention for families of children with ASD, ParentWorks-Spectrum. This brief (12-session) intervention integrates three skills-based modules addressing (1) Disruptive child behaviours that often co-occur with ASD in young children (e.g., tantrums; aggression); (2) Core features of ASD related to Social and Communication skills; and (3) Parent Wellbeing (e.g., parental stress).

Method: A case series was conducted with ($N = 8$) clinic-referred two-parent (mother and father) families who had a child (male $n = 7$; female $n = 1$) diagnosed with ASD, aged between 2 and 5 years 11 months ($M = 4.25$ years, $SD = .707$).

Results: Parent-report data indicated that the intervention was acceptable and feasible, and associated with low attrition rates and high levels of engagement. Moreover, significant reductions in child behaviour difficulties were observed. Seven children demonstrated reliable reductions in both the frequency and number of behavioural difficulties across the intervention.

Conclusions: These findings provide preliminary support for Parentworks-Spectrum, and support the further evaluation of this brief, integrated intervention for families of children with ASD, in future research.

Keywords: Autism Spectrum Disorder; Parent Mediated Intervention; Behavioural Intervention; Early Intervention.

Introduction

The impact of autism spectrum disorder (ASD) is often far-reaching, impacting multiple domains of life for the individuals diagnosed as well as their families. Children with ASD have higher rates of comorbid psychiatric disorders relative to children without ASD [1]. Co-occurring behavioural difficulties (including aggression, non-compliance, and tantrums) are highly prevalent and can interfere with the acquisition of new skills and participation in daily routines [2, 3]. Parents also show significantly higher levels of stress and poorer well-being [4]. ASD is associated with significant social and economic costs, and places considerable burden on the public health and education systems [5]. Although no existing treatment is capable of removing

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the core symptoms of ASD, there is emerging evidence that early intervention can alter developmental trajectories and optimise long-term outcomes.

Considerable progress has been made in the development of parent mediated interventions (PMIs) for children with ASD in recent years. Research has demonstrated the potential for these interventions to benefit both core ASD symptoms and behavioural difficulties, including improvements in children's communication skills and adaptive behaviour [6, 7], joint attention and verbal language skills [8-10], in addition to reductions in ASD symptoms [11], behavioural difficulties [12, 13] and parent stress [14]. Evidence has also raised questions about the level of intensity needed for PMIs to bring about change for children with ASD. While the time and intensity recommended for autism interventions has been greater than for other childhood disorders, there is evidence to suggest that a brief integrated PMIs could be effective across multiple domains of child functioning. For example, there is emerging evidence that brief PMIs of 9 to 18 sessions can be effective in the short- and longer-term [11, 15]. Despite recent advances in the development of such interventions, many PMIs are lengthy, highly specialised, incur significant financial costs, and are not readily accessible for families [16, 17]. In qualitative research examining challenges faced by parents attempting to access treatment for their children with ASD over 70% of participants reported high levels of stress associated with accessing treatment, managing ASD symptoms, financial strain and liaising with multiple health care professionals [18].

In summary, it would seem highly beneficial to integrate and synthesise treatment components of existing PMIs into a brief but comprehensive intervention addressing the core ASD symptoms alongside child behavioural difficulties and parental/family functioning. Independently, PMIs can

produce positive and sustained outcomes for both parents and children. Research is now needed to examine the possible benefit that such an approach would yield for core social and communication skills, child behavioural difficulties and parent wellbeing.

In this paper we report on the preliminary evaluation of a novel, integrated, brief parent mediated intervention, ParentWorks-Spectrum [19] for young children with ASD and their families, and its potential impact on child behavioural difficulties, child social and communication skills and parent wellbeing. This was done using a small case series design. It was predicted that the intervention would be feasible, with high rates of attendance, participant retention, engagement, and parental satisfaction with the intervention. It was further predicted that children (>50%) would demonstrate significant improvements in disruptive behavioural difficulties and social communication skills and that significant improvements would be observed in parent reports of wellbeing and perceived competence.

Methods

Participants

Participants were (N = 8) self-referred two-parent families who had a child (male n = 7; female n = 1) diagnosed with ASD (level 2 or level 3) aged between 2 and 5 years 11 months (M = 4.25 years, SD = .707) seeking assistance with managing disruptive behaviours. Three families participated with the mother participating only and five families participated with both parents (mother and father) participating in intervention sessions. All children met diagnostic criteria for Oppositional Defiant Disorder (ODD) at pre intervention assessment. Socio-demographic information is summarised in Table 1. The eligibility criteria for the study are provided in Appendix S1.

Table 1: Demographic Information and Clinical Characteristics of participating families

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	Range	Freq	%
Child age (years)	8	4.25	0.707	2-5		
Child gender (male)	8				7	87.5
Treatment as usual (hours)	8	1.68	0.799	1-4		
Child diagnosis	8					
ASD diagnosis					8	100
ODD diagnosis					8	100
ODD rating		4.88	0.835	4-6		
ADHD diagnosis					5	62.5
ADHD rating		3.63	1.76	1-4		
Anxiety diagnosis					3	37.5
Anxiety rating		1.63	2.26	1-5		
Developmental delay	8				5	62.5
Medication	8					

Stimulant					3	37.5
Antipsychotic					1	12.5
Household income	5					
\$101-160000					2	25
>\$160000					3	37.5
Prefer not to specify					3	37.5
Mother's education level	8					
Year 12 or less					1	12.5
TAFE/Diploma					1	12.5
Undergraduate degree					4	50
Postgraduate degree					2	12.5
Father's education level	8					
Year 12 or less					1	
TAFE/Diploma					1	
Undergraduate degree					4	
Postgraduate degree					2	
Two-parent family					8	100

Procedure

The current study took place at the University of Sydney Child Behaviour Research Clinic (CBRC) and was approved by the University of Sydney Human Research Ethics Committee (Project No. 2018/716). Written informed consent was obtained from participating parents prior to commencing the study. An initial assessment session was then conducted prior to parents commencing the intervention with a psychologist. A post intervention assessment was conducted within 2 weeks of parents concluding the intervention. The primary caregivers, who were mothers in this study, completed all parent report measures unless otherwise specified. Measures were completed pre and post intervention unless otherwise stated. The full research procedure is provided in Appendix S2.

Intervention: ParentWorks-Spectrum

The 12-session intervention ParentWorks-Spectrum (Leonard et al., 2019) draws from the theoretical foundations and evidence-based treatment components of PMIs for ASD, and an evidence-based parenting intervention based on social learning principles, attachment theory, and family systems theory (20). This 6-to-8 session parenting intervention was developed primarily for children aged two to eight years old with conduct problems and has been adapted for a range of populations in previous research (e.g., Dadds, English, Wimalaweera, Schollar-Root, & Hawes, 2019; Dadds, Thai, et al., 2019). Core modules include behaviour management strategies and partner support strategies to facilitate parents' general wellbeing reduce partner discord and increase consistent parenting practices. Parentworks-Spectrum builds on this intervention to target and quantify three core intervention components: 1) disruptive behaviours; 2) child

social and communication skills and 3) parent wellbeing. This is a 12-session parent mediated integrated intervention delivered to parents over 12 weeks (12x 1-1.5 hour 1:1 session per week) that provide parents with specific strategies across the aforementioned areas. An overview of intervention components is summarised in Table S1.

Measures

Diagnostic Interview

Diagnostic Interview Schedule for Children, Adolescents and Parents (DISCAP-5) [21] is a clinician administered semi-structured diagnostic interview for assessing psychiatric disorders in children and adolescents. This diagnostic system is a reliable indicator of externalizing and internalizing disorders with a rating of 4 or greater indicating that the DSM-5 criteria has been met[(21)].

Treatment as Usual

Information regarding engagement in other interventions and/or healthcare services (intervention frequency) was collected pre and post intervention.

Treatment engagement

Parents' engagement was collected weekly after the completion of each intervention session through a brief parent report questionnaire. Parents were asked to rate the following statements from 0 (not at all) to 4 (fully); (1) How engaged were you in the therapy session? and (2) To what extent did you actively implement the treatment program in the home between sessions?

Treatment acceptability

Information regarding treatment acceptability was

collected through a parent self-report questionnaire post intervention. Refer to Appendix S3.

Social and communication skills

The Social Responsiveness Scale [22] is a 65-item parent-rated scale for measuring the severity of ASD symptoms in children from 3 to 18 years of age. The total SRS score provides a clear picture of a child's social and communication skills, assessing domains of communication, social interactions and repetitive and stereotyped behaviours and interests. The SRS has been utilised extensively in ASD intervention studies [23] and has been found to have high internal consistency ($\alpha=0.95$; Constantino & Gruber, 2012).

Disruptive Behaviours

The Eyberg Child Behaviour Inventory [24] is a 36-item parent-report measure of externalizing behaviour in children aged 2 to 16 years. The ECBI has two scales: 1) the Intensity scale assesses the frequency of disruptive child behaviours and 2) the Problem scale assesses the total number of disruptive behaviours reported by parents. The ECBI demonstrates good test retest reliability ($\alpha \geq .75$) and internal consistency for the Intensity ($\alpha \geq .90$) and problem ($\alpha \geq .85$) scales has been utilised widely in ASD parenting intervention studies [25-28].

Parent depression, anxiety and stress

The Depression Anxiety and Stress Scale (DASS-21) developed by Lovibond and Lovibond (30) measures the severity of a range of symptoms common to depression, anxiety and stress over the previous week. Each item is scored on a 4-point scale from 0 (did not apply to me at all) to 3 (applied to me very much or most of the time). The DASS-21 has been reported to have high internal consistency for depression ($\alpha = 0.88$), anxiety ($\alpha = 0.82$) and stress ($\alpha = 0.90$) subscales [31].

The Parenting Stress Index Short Form [32] is a 36-item parent-report measure assessing the level of stress experienced by parents of children from 1 month to 12 years. The scale has been used widely with parents of children with ASD including intervention research (e.g., 29) and has been reported to have high internal consistency for the total score [32].

Results

Analytical plan

Two criteria were applied to examine treatment change across participants from pre to post intervention for outcome measures. Firstly, the Reliable Change Index (RCI) [33] was calculated to examine the extent to which changes in parent and child outcomes were clinically significant. This approach provides a reliable indication of significant treatment change for individual participants across multiple time points [34] and has been utilised in other studies with small sample sizes (e.g., Ginn et al., 2017). Secondly, a participant was determined to have clinically significant change if the participant's scores were within a clinical range at pre-intervention and then within a non-clinical range post-intervention. The number and proportion of children and parents demonstrating clinically significant treatment change from pre-post intervention according to these criteria are shown in Table 2. Figure 1 displays the means for primary outcome measures at pre- and post-intervention.

The Reliable Change Index (RCI) was used to determine whether the magnitude of change exceeded the margin of measurement error. RCIs greater than 1.96 represent a reliable change conservatively assuming a Cronbach's alpha of 0.75.

Treatment attrition and engagement

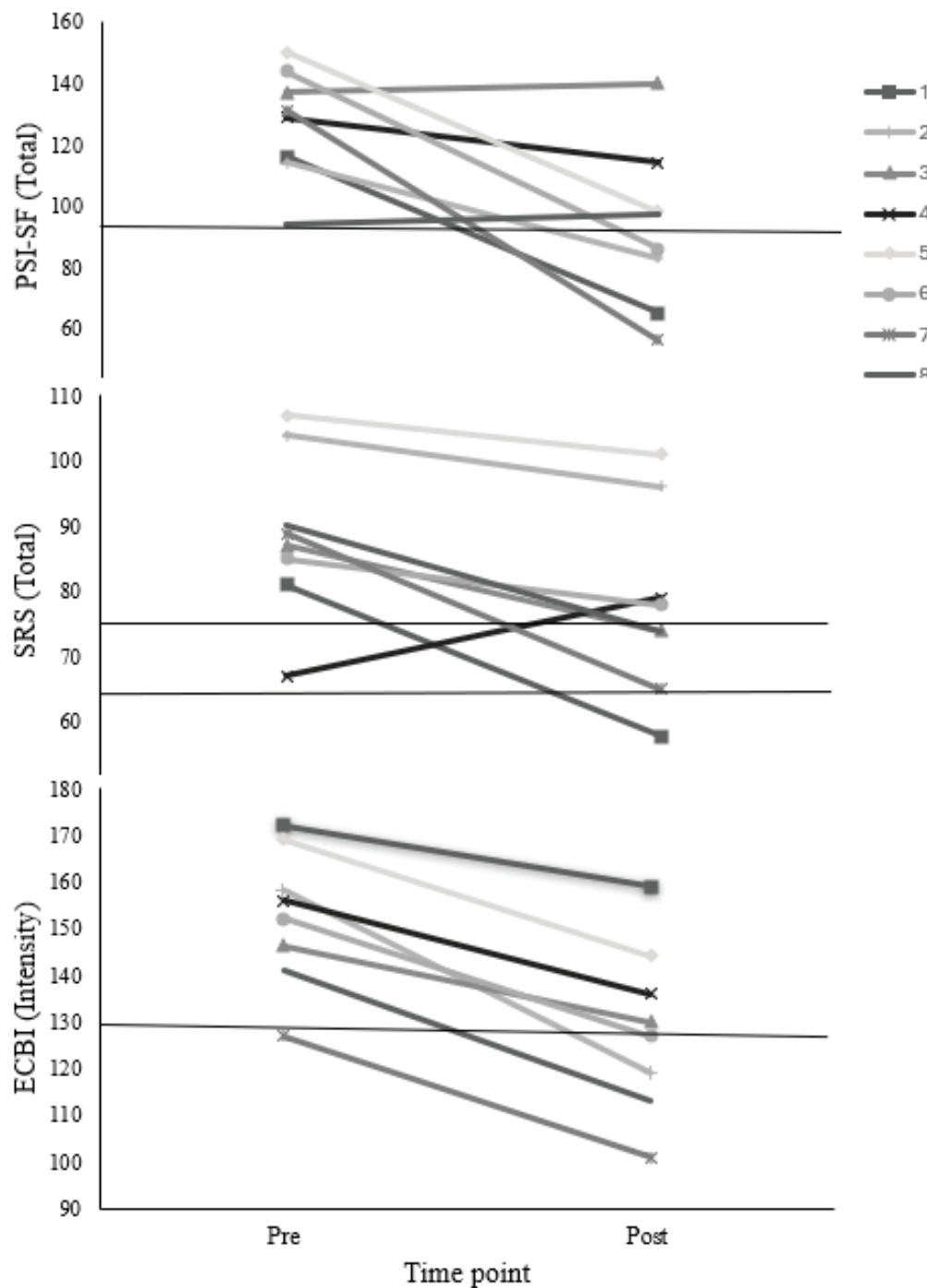
All participating parents were retained and completed the 12-week intervention. Parents' self-reported weekly

Table 2: Clinical and Reliable Change at Post-Intervention assessment

RCI > 1.96	RCI		Clinical Significance	
Measure	n/n	%	n/n	%
Eyberg Child Behaviour Inventory				
Intensity	5/8	62.5	4/8	50
Problem	5/8	62.5	4/8	50
DISCAP ODD	-	-	6/8	75
Social Responsiveness Scale Total	1/8	12.5	2/8	25
Parent Stress Index-Short Form	6/8	75	4/8	50
Depression Anxiety and Stress Scale 21				
Depression	3/8	37.5	3/8	37.5
Anxiety	2/8	25	2/8	25
Stress	0/8	0	2/8	25

The Reliable Change Index (RCI) was used to determine whether the magnitude of change exceeded the margin of measurement error. RCIs greater than 1.96 represent a reliable change conservatively assuming a Cronbach's alpha of 0.75.

Note: DISCAP = Diagnostic Interview Schedule for Children, Adolescents and Parents (DISCAP-5); ODD = Oppositional Defiance Disorder



Note. Clinical cut offs are represented with black horizontal lines and are as follows: ECBI Intensity = 130; SRS= 66-75; PSI-SF=90.

Figure 1: Mean ECBI (Intensity), SRS and PSI-SF scores at pre- and post-intervention

Note. Clinical cut offs are represented with black horizontal lines and are as follows: ECBI Intensity = 130; SRS= 66-75; PSI-SF=90.

engagement in treatment and implementation of treatment strategies were as follows. All mothers ($n = 8$) reported on average that they were fully engaged during treatment sessions ($M = 4$) and that they were able to mostly ($n = 1$) or fully ($n = 7$) implement the treatment strategies at home

in between sessions ($M = 3.87$). Participating fathers ($n = 5$) reported on average that they were fully engaged in treatment sessions ($M = 4$) and that they were able to somewhat ($n = 1$), mostly ($n = 1$) or fully ($n = 3$) implement treatment strategies in between sessions ($M = 3.40$).

Treatment acceptability

Data regarding acceptability of the treatment were obtained through parent self-report questionnaire completed post-treatment. The majority of parents either responded 3 (mostly) or 4 (very much) to the 14 items ($M = 3.80$). Feedback that parents provided in the optional free text feedback section of the questionnaire included: 1) follow up/ booster sessions after the 12-week intervention concludes would be beneficial ($n = 2$); 2) the feedback and formulation session was helpful in understanding child issues and how they can impact the whole family ($n = 1$); 3) reviews at the beginning of sessions were helpful to recap treatment strategies and problem solve issues ($n = 2$); 4) less questionnaires would be appreciated ($n = 1$). No adverse events were reported.

Treatment as Usual

Parent reported treatment as usual did not change from pre to post intervention.

Disruptive behaviours

At post-intervention ($n = 5$) of the children demonstrated reliable reductions according to mothers' reports on the ECBI in both the intensity and number of behaviours endorsed. All children demonstrated clinical change according to DISCAP-5 assessments on the severity of ODD diagnoses. With regards to diagnostic ratings of ODD diagnosis, ($n = 5$) children did not meet diagnostic criteria, ($n = 1$) child demonstrated sub-clinical levels and ($n = 2$) children demonstrated a reduction in ratings but still met diagnostic criteria post-intervention.

Social and communication skills

At post-intervention, ($n = 1$) of the children demonstrated reliable reductions on mothers' reports on the SRS total score.

Maternal stress anxiety and depression

At post-intervention, ($n = 6$) mothers demonstrated reliable change on the total score of the PSI-SF with ($n = 4$) reporting clinically significant change. With regards to DASS-21 scores, at post-intervention ($n = 3$) mothers demonstrated reliable and clinically significant change on the depression scale and ($n = 2$) on the anxiety scale. For the stress scale, ($n = 2$) mothers reported clinically significant change however no reliable change was detected.

Discussion

This case series represents the first description and empirical exploration of ParentWorks-Spectrum, a novel integrated parent mediated intervention for children with ASD and their parents that adopts an integrated treatment approach focusing on supporting both parents and children. Overall, the findings from this study suggest that the intervention was feasible, acceptable and resulted in clinically significant treatment effects for both children and parents. It is acknowledged that any inferences regarding treatment

effects must remain preliminary due to the small sample size of this study.

This proof-of-concept study aimed to firstly examine the feasibility and acceptability of ParentWorks-Spectrum for parents who have a young child with ASD. The absence of attendance attrition in conjunction with parent reports of treatment engagement and implementation and parent responses on a satisfaction questionnaire indicate that the intervention approach is feasible and acceptable to parents. The other aims of this research were to examine potential treatment effects on child behavioural difficulties, child social and communication skills and parental wellbeing. The findings of the current study provide partial support for the hypothesis that improvements would be observed in both child and parent outcome variables.

A key finding of this study was the reduction in mothers' reports of child behaviour problems after a 12-week intervention where approximately 4 sessions focus on managing behavioural difficulties. Five children demonstrated both reliable and clinically significant reductions in both the frequency and number of behaviour problems reported by mothers on the ECBI post-intervention. All children met diagnostic criteria for ODD pre-intervention, and six demonstrated clinical reductions in ODD symptoms according to DISCAP-5 ratings post-intervention. With regards to clinical significance, five children no longer met diagnostic criteria for ODD post-intervention. These results are consistent with a growing body of research indicating that behavioural difficulties in children with ASD are amenable to change through brief PMIs [13, 35]. Whilst the majority of children demonstrated reductions in disruptive behaviours, only one child was observed to make reliable improvements in social and communication skills as indicated by mothers' total post-intervention scores on the SRS. It is suggested that some children with ASD may require a longer, more intensive treatment for observable changes in social behaviours to emerge. Intervention for social and communication skills may be influenced by a number of factors including IQ, developmental and/or cognitive delays, the length of the treatment and follow up period and the heterogeneity of ASD (Dawson [36]). This is an area that warrants further investigation.

With regards to parenting outcomes, most mothers demonstrated reductions in parent stress related to parenting with six mothers showing reliable reductions and four demonstrating clinical change post-intervention on the PSI-SF. With regards to mental health, four mothers fell within the clinical range for depression, three for stress and five for anxiety on the DASS-21 at pre-intervention. At post-intervention, three mothers demonstrated clinical reductions in depression and two for anxiety and stress. These results are promising and highlight the need for interventions to incorporate strategies to support parents although additional

research is required to identify the effectiveness of individual treatment components in supporting parent wellbeing.

Several methodological issues need to be considered. Firstly, in the absence of a control condition it is not possible to rule out that reported changes from pre-post treatment may be attributed to factors other than the intervention. Given that the parents had a high socio-economic status, and all children had moderate to severe behavioural difficulties in the current study, the generalisability of the treatment remains unclear. Families participating in the current study may have had less barriers to treatment engagement and higher rates of engagement than is typical of the general population. Another limitation of this research was the use of maternal reports for several treatment outcomes, although improvements were also found for diagnostic ratings made by clinicians. Future research should aim to examine the potential treatment effects in a broader sample of children and families with varying levels of behavioural difficulties and socio-economic status.

Conclusion

In conclusion, this case series forms the first preliminary efficacy for the implementation of ParentWorks-Spectrum as a brief integrated parent program that is not limited to factors affecting the child but actively focuses on the contextual factors affecting the broader family system. Parents overall satisfaction with the intervention in conjunction with the observed improvements in both parent and child factors suggest that this integrated treatment approach which places increased emphasis on parental wellbeing and the family system is feasible. The findings of this study form the first preliminary empirical support for Parentworks-Spectrum an integrated parent mediated intervention that aims to improve the way in which parenting programs are delivered for children with ASD and their families.

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Ethical information

Parents provided written informed consent prior to participating in this study approved by the University of Sydney Human Research Ethics Committee (project No. 2018/716).

Declaration of Competing Interests

The author(s) declare no potential competing interests with respect to the research, authorship, and/or publication of this article.

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