

Original Research

Understanding Autism and understanding my child with Autism: An evaluation of a group parent education program in rural Australia

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Abstract

Objective: To describe and evaluate a six-session program provided to parents of children with Autism in rural Australia. The program was designed to improve parent's knowledge and understanding of Autism, improve their confidence in managing their child and decrease parental anxiety.

Design: A self-constructed questionnaire administered pre- and post-intervention.

Setting: An early intervention centre in a large town in rural Victoria.

Participants: Ninety-eight parents (or family members) of young children primarily aged 2–6 years of age, diagnosed with Autism.

Interventions: A 'multi-stranded content' program was offered over six evenings. Ten programs were conducted over six years.

Results: The pre- versus post-session analysis using a paired t-test on matched person-to-person parental responses (n = 92) showed significant increases in parental understanding of Autism and understanding of their own child (P < 0.001), and in understanding the

communication, sensory, social, learning and behavioural features of Autism (P < 0.001). Significant increases in parental confidence and a significant reduction in parental anxiety were also shown (P < 0.001). Qualitative data indicated that parents valued learning about the general nature of Autism and sensory processing, and reported feeling less alone.

Conclusions: The six-week program was successful in terms of its aims. Parent feedback indicated that ongoing parent education sessions at regular intervals would enhance the impact of the program.

KEY WORDS: Autism, multi-stranded content, parent education, parent group, rural.

Introduction

Australian prevalence figures indicate that one in every 160 children has Autism Spectrum Disorder (ASD).¹ (In this text, ASD collectively refers to Autism, Aspergers and all Pervasive Developmental Disorders (PDD)). Children with ASD experience the world in a different way because of the neurological differences which characterise the disorder.² In discussing the UK Early Bird Program, Whitaker³ reports that the most frequently expressed unmet need for parents of children with ASD, at the point of diagnosis, is access to quality information about ASD generally and particularly the specific manifestation in their own child. For parents, the strategies that might have been effective with other children are often not effective with a child with ASD,⁴ highlighting a need for more specific information and support to parents.

Stress levels for parents of children with ASD are significantly higher than those reported by parents of children with almost any other type of disability or health problem.^{5–7} ASD in a child is associated with increased burden and stress for parents⁸ with frequent anti-social

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At the time the courses were run, Judy also worked for W.E.C.A.N, an early intervention service in rural Australia.

(Judy co-wrote the 'Understanding Autism and Understanding my child with Autism' program, designed the questionnaires, collected data and wrote an initial draft of the paper, which was subsequently revised and rewritten in collaboration with Dr Andrea Reupert.)

(Andrea revised, assisted and supervised with the paper as part of a PHCRED strategy through Monash University Department of Rural and Indigenous Health Gippsland.)

All programs were carried out at the W.E.C.A.N. premises Warragul Victoria.

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What is already known on this subject:

- *Having a child with Autism Spectrum Disorder (ASD) is stressful for parents.*
- *Rural parents of children with ASD are further disadvantaged because of less availability and access to intervention, health, educational and support services.*
- *Group-parent education programs for parents of children with Autism have shown positive outcomes but have not been widely utilised.*

What this study adds:

- *A description and evaluation on a six-week group parent education program for families with a child with ASD living in rural Victoria.*
- *Quantitative and qualitative data demonstrate the benefits of a group parent education program with multi-stranded content.*
- *A six-week program can be helpful to parents living with a child with ASD.*

behaviour problems, irritability, agitation and obsessive behaviours adding to the frustration of not being able to understand their child.^{7,9} Compared to urban families, those living in rural areas lack proximity to disability support and educational services,¹⁰ reduced access to transport, fewer early childhood services, reduced specialist services,¹¹ fewer allied health workers¹² and a lower number per capita of doctors.^{13,14}

Brookman-Frazeo *et al.*¹⁵ argue that group parent education is an efficient and cost effective way to reach large numbers. Group sessions provide a forum for parents to support and learn from each other and reduce isolation.⁷ However, a systematic review of interventions for parents of ASD children found only 18% occurred within a group setting,¹⁵ suggesting that group parent programs for families of children with ASD have not been used widely.

Three large randomised control studies (RCTs) in Australia^{8,16,17} have shown positive outcomes for group parent education programs. Time frames for these programs varied from one day to 20 weeks, with no substantive conclusion regarding optimal program length. We believe that six weeks allow sufficient time for parents to absorb information, practice strategies and develop mutual support while not being too long for parents to commit to and organise child care for. In terms of program foci, Roberts⁷ highlights the need for broad program content. Providing content that is broad or 'multi-stranded' (rather than a single-focus or strictly behavioural model) helps parents to appreciate the underlying factors which might be contributing to their child's behaviour,^{4,7,8,18} although the actual content varies between programs.

Apart from these published papers,^{7,8,16,17} there is a paucity of documented Australian group education programs for parents of a child with ASD, especially in rural settings. Thus, the 'Understanding Autism and Understanding My Child with Autism' (UA) program was developed within an early intervention setting in rural Victoria.

Method

Program description

The UA program was developed by Judy Farmer (Occupational Therapist) and Dr Harvey Miller (head of a regional family counselling/training centre) as a group parent education program consisting of six, two-hour, weekly sessions. The program was specifically developed for rural families who have limited access to intervention and support services.

This program's multi-stranded content delivered information about ASD and the differences in communication, sensory, social, thinking and behaviour for children with ASD. The particular and unique differences for children diagnosed with Aspergers were also presented. Practical strategies were presented to parents to utilise with their child. A healthy group dynamic was promoted with parents encouraged to listen to one another, share their stories, support each other and explore their experiences.

The program aims were:

1. Help parents 'see' and understand their child through understanding the nature of ASD and the communication, social, sensory, play and thinking issues pertinent to ASD.
2. Gain confidence in dealing with, and pre-empt difficult child behaviours by developing a personal 'tool kit' of practical resources and strategies.
3. Decrease feelings of isolation by encouraging inter-parent support and sharing.
4. Decrease parental anxiety by providing information and support.

Program information was presented using multiple media (e.g. power point slides, DVD excerpts) and a 72-page manual (see Table 1). The program content remained the same during the 10 courses but with minor modifications to incorporate new research, information and resources. After the first program where 'Play' was the topic in week 5, a parent participant presented her

story. This was well received so this feature remained throughout ensuing courses.

Program evaluation

The program was evaluated by a self-constructed pre/post questionnaire, consisting of 15 questions (Table 2) and based on program aims. Parents were invited to rate

their response on a 0–5 point Likert scale at the start of week 1 and at the end of week 6. Additional, open-ended questions were provided about their expectations (pre) and their experiences (post).

Participants

Participants were referred from a range of educational and health providers. Group numbers ranged from five to 16 participants. Over the six years, 102 people started the course, 98 attended four weeks or more with a dropout rate of 3.92% (Table 3). Of the 86 parents who attended four to six sessions, (the other 12 were family members), 13 came on their own (15% of this group), while 73 attended with another person (85%).

A total of 79 children with ASD were represented by participants; 52 (66%) were aged 2–6 years, and 27 were older than 6 years (34%). Data were not collected on socioeconomic background but anecdotally participants included a range of demographic groups.

Results

Pre/post Likert questions

Pre- and post-questionnaire results are presented in Table 4 and Figure 1.

Error bars in Figure 1 represent 95% confidence intervals. An analysis on all individual Likert scale data

TABLE 1. *Outline of ‘Understanding Autism and understanding my child with Autism’ program*

Week 1	What is Autism?
Week 2	Sensory processing and how this impacts children with Autism
Week 3	Communication and the receptive and expressive issues for children with Autism Spectrum Disorder (ASD)
Week 4	Social understanding and the difficulties for children with Autism
Week 5	Learning from someone who really knows: a parent’s perspective
Week 6	Understanding behaviour: From a PRE (physical receptive environment) model developed by the program authors, together with behavioural strategies of modelling shaping and reinforcement

TABLE 2: *Likert scale questions used on pre- and post-questionnaires for ‘Understanding Autism and understanding my child with Autism’ program*

Section 1 Understanding of Autism	Q1	How much do you know about the general nature of Autism Spectrum Disorder (ASD)?
	Q2	How much do you know about how ASD develops?
	Q3	How much do you know about what a diagnosis of ASD means for your child?
Section 2 Understanding my child	Q4	How much do you understand about ASD and its impact on your child’s learning or cognitive development?
	Q5	How much do you understand about ASD and its impact on your child’s language and communication?
	Q6	How much do you understand about ASD and its impact on your child’s development of appropriate social skills?
	Q7	How much do you understand about ASD and its impact on your child’s sensory processing?
	Q8	How much do you understand about ASD and its impact on your child’s behaviour?
Section 3 Personal confidence and capacity	Q9	How confident are you that you can help your child reach his/her potential?
	Q10	How confident are you that you can manage specific behavioural issues related to your child
	Q11	How confident are you that you can help your child cope at playgroup, preschool or school?
	Q12	How confident are you that you can help your child find their place in the world
	Q13	What is your current level of anxiety?
	Q14	How confident are you that you can access resources to support your child?
	Q15	How confident are you that you can educate others about your child?

points was done using a paired *t*-test on each question, looking at pre/post changes for those parents who attended the program for four or more weeks where both a pre- and post-course questionnaire had been completed (*n* = 92). Matched pre/post data were not available on the remaining six parents so their data were not used.

Question 13 asks parents to reflect on their level of anxiety. Unlike the other questions, the change in pre/post reflected a decrease in anxiety on a scale of 0–5. The reported anxiety scores have therefore been inverted for ease of the interpretation. The other questions all reflect an increase in knowledge and confidence on a scale of 0–5.

The direction of change for all the questions was positive and statistically significant (*P* < 0.001). The

TABLE 3: Summary of participants of 10 ‘Understanding Autism and understanding my child with Autism’ programs

Participant demographic	<i>n</i>	%
Male	35	36
Female	63	64
Parent	86	88
Family member	12	12
Attendance		
6 weeks	66	67
4–5 weeks	32	33
Children represented		
Aged 2–6 years	52	66
Aged 6+ years	27	34

TABLE 4: Paired *t*-test results on 15 questions comparing individual participant before and after responses for the ‘Understanding Autism and understanding my child with Autism’ program. *n* = 92

	Mean Pre	95% CI lower	95% CI upper	Bar low	Bar high	Mean Post	95% CI lower	95% CI upper	Bar low	Bar high	<i>P</i> -value
Q1	2.14	1.93	2.35	0.21	0.21	4.0	3.92	4.14	0.11	0.11	<0.001
Q2	1.29	1.06	1.53	0.23	0.24	3.8	3.61	3.92	0.16	0.15	<0.001
Q3	1.92	1.67	2.17	0.25	0.25	4.0	3.82	4.07	0.13	0.12	<0.001
Q4	1.80	1.60	2.01	0.20	0.21	3.9	3.74	4.06	0.16	0.16	<0.001
Q5	1.97	1.77	2.17	0.20	0.20	4.0	3.86	4.17	0.16	0.15	<0.001
Q6	1.91	1.70	2.13	0.21	0.22	3.9	3.74	4.03	0.15	0.14	<0.001
Q7	1.92	1.71	2.14	0.21	0.22	4.0	3.83	4.16	0.16	0.17	<0.001
Q8	1.90	1.69	2.12	0.21	0.22	4.0	3.83	4.15	0.16	0.16	<0.001
Q9	2.00	1.80	2.20	0.20	0.20	3.5	3.32	3.68	0.18	0.18	<0.001
Q10	1.89	1.67	2.11	0.22	0.22	3.6	3.4	3.71	0.15	0.16	<0.001
Q11	1.80	1.45	2.16	0.35	0.36	3.2	2.86	3.48	0.31	0.31	<0.001
Q12	1.41	1.09	1.74	0.32	0.33	3.1	2.72	3.43	0.35	0.36	<0.001
Q13	1.55	1.26	1.85	0.29	0.30	3.3	3.03	3.59	0.28	0.28	<0.001
Q14	2.50	2.16	2.84	0.34	0.34	3.9	3.71	4.15	0.22	0.22	<0.001
Q15	2.27	1.98	2.57	0.29	0.30	3.9	3.74	4.12	0.19	0.19	<0.001

non-parametric Wilcoxin signed ranked test was also done on the averages of each group also showing positive changes.

Open-ended questions

Responses to the open-ended questions regarding the key things the participants had learned, and the most helpful or valued parts of the program, were analysed using inductive thematic analysis.¹⁹ Analysis began by carefully reading each response, highlighting expressed ideas and sorting these into common themes.¹⁹

At the beginning

The feelings most frequently expressed at the start of the program were confusion, frustration and hope that things might improve. ‘I am overwhelmed by the impact of Autism on my family. I know so little about it and yet this is a huge impact on my child.’ Many stated that they did not have sufficient information and were feeling lost ‘in the system’. Many parents reported being nervous or fearful of what they might learn but were also determined to learn.

Parents’ perspectives at program end

Table 5 shows the parental comments grouped under collective themes and the number of responses across the 10 courses with the most prominent detailed below

1. *Understanding Autism and my child.* Most expressed relief in knowing there were ‘real’ differences

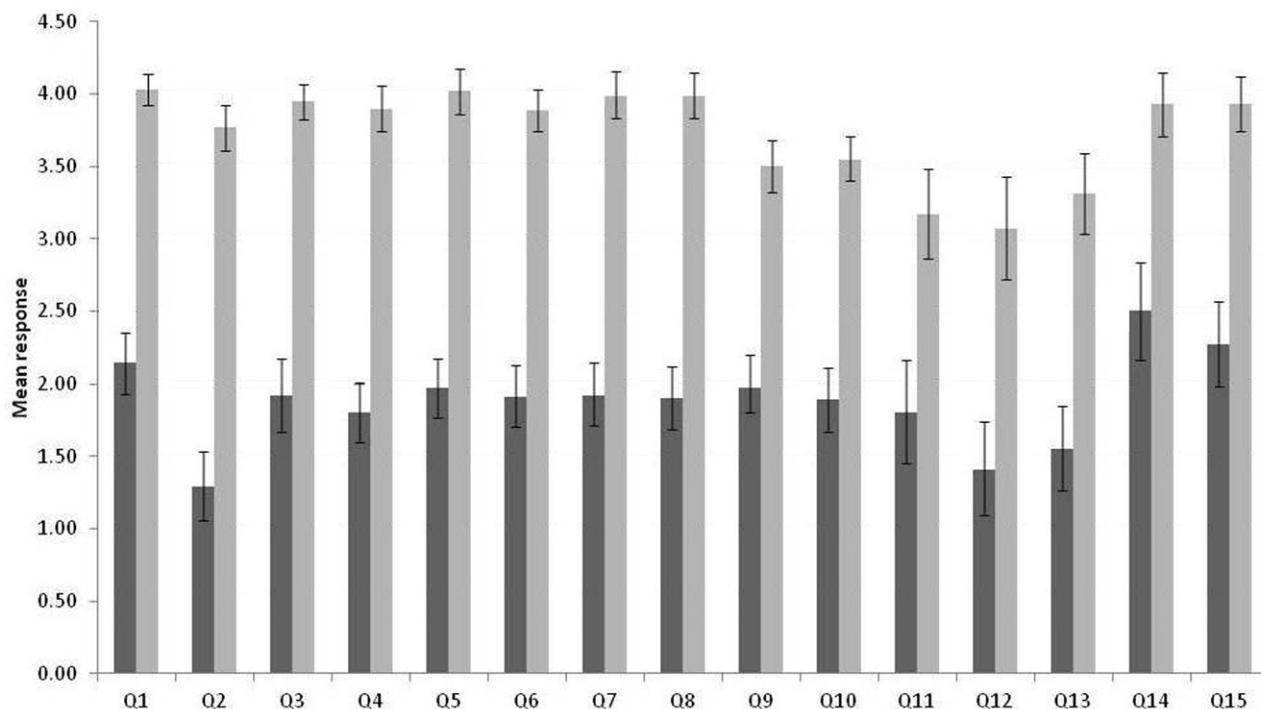


FIGURE 1: Paired t-test results on 15 questions comparing before and after individual responses for the ‘Understanding Autism and understanding my child with Autism’ program in a graphical format (n = 92) with error bars. (■) Pre-course; (□) post-course.

TABLE 5: Themes from post questionnaires qualitative responses regarding things learned and things most valued from ten ‘Understanding Autism and understanding my child with Autism’ programs

Themes from qualitative parent responses	No. of responses
1. Understanding Autism/my child	55
2. We are not alone	45
3. Understanding sensory processing.	44
4. Presenter skills	35
5a. Self confidence	34
5b. Observation/looking carefully/investigate/detective	34
5c. Positive behaviour management	34
6. Practical resources given out in addition or used in program	31
7. Learning and using social stories/social strategies	26
8. Understanding communication issues/practical ideas	25
9. The program manual	16
10. Another parent’s story: her journey	13
11. ‘Other’: importance and use of play/teaching strategically/using obsessions	5

to explain their child’s thinking and behaviour, and as a consequence, reported accepting and understanding their child better. Parents indicated that having an accurate picture of the differences at a neurological and practical level helped them accept their child. They especially valued the presentation of the genetics, neurobiology and outcomes for children and adults with ASD.

‘I feel as if I now understand what it’s like in my son’s world. I now know what Autism is.’

2. *We are not alone.* Parents appreciated being part of a small group and having the opportunity to share their story and hear from others. Many reported feeling supported and as a result less isolated.

Attending the program has reduced my feelings of isolation; just hearing other family’s experiences has allowed me to feel ‘normal’ again.

3. *Understanding sensory processing.* Many emphasised that understanding their child from a sensory point of view made significant differences to the way they related to, and ‘managed’ their child. This understanding was in addition to their overall improved understanding of the general nature of Autism.

I need to stand back, take a moment and try to hear, smell and feel the situation as it may feel to my child. I understand now why my son behaves badly in some environments. I have [sensory] strategies and tools to help my son cope better.

Many indicated that understanding an ASD child's sensory processing in terms of over and under-sensitivity helped them accept and incorporate behaviours such as needing to 'wriggle' or move, their child's need for certain textures in clothing or something in their child's hand to 'fiddle with' and the time out their child might require from noisy environments, without these behaviours becoming a source of conflict.

4. Presenter skills. Specific presenter skills were identified including patience, sensitivity, promoting sharing and carefully guiding group discussions.

The presenters were open, warm and showed appreciation to all group contributions. Thanks for advice, compassion, direction and for sensitivity on often very painful topics. Everything was explained in simple but honest terms with lots of examples.

Parents also valued honest presentations that were not 'dumbed down'; additionally they valued the 'right' words being used and explained.

5. Self-confidence. Parents reported feeling confident to manage and support their child by taking the time to 'Look and listen' before acting.

I can do this! There is always a cause for behaviour. I need to plan for success. I need to accept my son for who he is and work with him, not against him. This is not my fault. It's not all negative, just a different kind of normal! I can make an enormous difference to helping my son!

Parents' comments/suggestions regarding the program

Parents indicated that six weeks was a good length. 'Six weeks is a good time frame for everyone to feel comfortable so they can share, although there is much to cover.' Parents requested sessions for extended family members, 'I wish every member of our family and friendship circle could do this course and learn what we have learnt and assist us putting it into practice and help us reinforce it', and for booster sessions. 'An annual follow up session could be very good to discuss and consolidate progress.'

The few negative comments related to some parents trying to monopolise the group particularly in the

course which had 16 participants. 'Some people interrupted too often and were always trying to talk about their own problems.'

Discussion

Quantitative data demonstrated significant pre/post change on each of the surveyed items including parental knowledge of ASD and confidence. A significant reduction in parental anxiety was also shown. The UK Early Bird Program^{3,4} found that providing information on the general nature of ASD helped parents appreciate how differently their child experienced the world – a finding affirmed here and by others.²⁰ Thus, providing accurate information to parents about the nature of ASD is important. The study also demonstrates that six weeks is sufficient to promote positive change in parents.

Other studies have examined parental anxiety after attending education programs though results vary. Roberts⁷ (p. 9) found an 'inconsistent effect on parental stress' with no statistical significance for a change in parental stress. Tonge *et al.*⁸ found that their group program was effective in reducing parental anxiety, particularly for parents who had higher levels of mental health problems. Similarly the data here demonstrated a decrease in parental anxiety over the six-week program.

Given that rural families live away from mainstream ASD intervention services, as well as family services, the positive results obtained from attending a six-week program are important. Having specific programs for rural families of children with ASD acknowledges the importance of rural 'distinctiveness' and the value of rural health practitioners working in a genuine multi-disciplinary way.²¹ The high-attendance rate (see Table 3) demonstrates the value parents placed on the program.

There is a growing understanding of the sensory differences experienced by people with ASD,^{22,23} and in this program, the most valued content strand was learning about the sensory aspects of ASD with practical sensory strategies to support their child. Concurrently, other areas of communication, social and understanding behaviour were also of value (Table 5). Such a result indicates that multi-stranded content could be incorporated into other education programs for parents of children with ASD. Parents highlighted the importance of mutual support and the opportunity to share stories with other parents. Repeated requests were programs for extended family as well as booster sessions.

The few negative comments related to group dynamics especially from the group of 16, suggesting that 10–12 participants may be the optimal size. Follow-up would also be valuable to assess how much parents have applied their new knowledge and confidence and how sustained the recorded gains were.

In terms of program length, content, group size, qualities and structure, this model may also be applicable to families living in urban areas and be a model that could be used by urban ASD service providers.

Limitations

There is no control or alternative intervention group data or long-term data. The self-constructed nature of the questionnaire is a potential shortcoming, as it is difficult to compare the results of this program with other parenting programs. It also needs to be noted that each parent will adapt and use the knowledge and strategies they have learned in different ways and in their own time. In addition, response bias, responding in the same manner to each item and variability in item interpretation are all known problems when using Likert scales.

Future studies might focus on fathers, on those parents who had a support person who attend the program with them versus those who did not and on differences in outcomes between parents of younger and older children.

Conclusions

Given the prevalence of ASD and the challenges associated with parenting a child with ASD, there is a need for parent education programs. In a rural context, where parents are isolated by distance and lack of services, this need is amplified. This paper described a six-week group parent education program with a multi-stranded content framework. The UA program is a short term, parent group education program which shows improved outcomes in parents of children with ASD. This paper provides encouragement to rural practitioners that a six-week multi-stranded group parent education program can be helpful to parents living with a child with ASD.

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