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The Incredible Years® Autism Spectrum and **Language Delays (IY-ASLD) Programme for Parents** delivered for

Northern Health and Social Care Trust (NHSCT)

Evaluation Report May 2018

By Maria McAleese & Angela Nesbitt







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Executive Summary

This report presents the results and assesses the effectiveness of the Incredible Years Autism and Language Delay Programme for parents/caregivers of children with Autism living in the NHSCT area. The programme was extremely well received, retaining eight of the nine parents recruited, securing high level outcomes for the families. A mixed methods research design was utilised to capture a rich picture of the participants' experiences. Findings from quantitative measures revealed overwhelmingly positive results; the programme demonstrated statistically significant improvements (with large effect sizes) across a number of parental ratings of the frequency of behaviours characteristic of Autism and the impact of these on the child's everyday functioning. Statistically significant decreases in parental stress levels (with a large effect size) occurred demonstrating how the programme can help lower caregivers' stress levels, improving their mental health and well-being. In addition, comparison of pre and post programme ratings of how problematic children's behavioural difficulties are at home showed statistically significant levels of change (with a medium effect size). Analysis of weekly session evaluations showed exceptionally positive ratings on all aspects of programme content. Qualitative information from the focus group interview presented a convincingly positive response regarding: how tailored the programme was for individual children; the new learning it entailed; how well the programme was delivered; the support it provided; and the impact it had on the participants' own parenting skills. Both facilitators loved this treatment programme for parents of children with Autism, reporting an extremely beneficial learning experience for all involved. Some recommendations are made for the effective delivery of such a high quality programme in the future.

PART ONE: RATIONALE, OBJECTIVES AND METHODOLOGY

Within the UK, approximately 1% of people are affected by Autism Spectrum Disorder (ASD); the diagnostic label given by the Diagnostic and Statistical manual of mental Disorders (5th ed.).

ASD is a lifelong neurodevelopmental condition characterised by core impairments in social interaction and communication, alongside rigid and repetitive patterns of behaviour, thoughts, interests and activities. Individuals with ASD also experience difficulties with executive functioning, emotional and behavioural regulation, motor control and sensory integration (American Psychiatric Association, APA, 2013). Despite these difficulties, ASD encompasses a spectrum of disorder, with many individuals presenting with an IQ within the average range and/or presenting with significant strengths within their cognitive learning profiles (Howlin, Magliati & Charman, 2009).

According to the Department of Health in Northern Ireland (NI), the estimated prevalence of Autism within the school aged population has increased by 1.3 percentage points from 1.2% in 2008/09 to 2.5% in 2016/17, with a male to female prevalence ratio of 4:1. The urban population within NI was found to have a statistically significant higher prevalence rate than the rural population with the rate of autism in the most deprived areas rated as 47% higher than the least deprived areas, and 42% higher than the NI average.

Within NI, individuals with ASD are afforded protection of their equality and rights by the Autism Act (NI) 2011. According to the Department of Health, 63% of young people with ASD were at Stage 5 of the Statutory Assessment of Special Educational Needs (SEN) process necessitating the Education Authority to make statutory assessments of their SEN.

Need for Parental Support

Children and young people on the Autism Spectrum are unique individuals with unique needs and abilities. However, many face challenges and issues on a daily basis which can present significant difficulties for parents and parenting. Many children with ASD present with associated behavioural difficulties, such as aggression, and co-morbid conditions such as ADHD, OCD and conduct problems. Aggressive behaviour in children can contribute to high levels of caregiver distress and parental mental health difficulties over and above stressors associated with core ASD conditions. The case for effective parental intervention in the early years is therefore paramount for longer term developmental outcomes for children.

Matson, Mahan and Matson's (2009) review of parent training programmes found this type of support to be a helpful way of equipping parents of children with ASD with new skills to be tried at home. Parent training with parents of children with ASD has been found to be effective in decreasing behavioural problems, improving parenting approaches, and equipping caregivers with skills to promote the

development of their children's communication and language skills (McConachie, 2005; Whittingham, 2008). Research by Dababnah and Parish (2016) highlighted the additional benefit of providing social support through the provision of parent group training.

Development of the recent IY-ASLD Programme

The Incredible Years® (IY) BASIC parent programme is a globally researched, manualized programme for parents of children aged 2 – 8. The programme promotes positive relationship building strategies to assist parents in managing children's behavioural problems (Webster-Stratton,2011). This program has been widely researched as effective in decreasing problematic behaviour in children (Webster-Stratton, 2011; Hutchings, Bywater and Daley, 2007) and in reducing parental stress and depression (Hutchings, 2012, and Charles et al, 2013). Although research has highlighted the effectiveness of the BASIC program with many parents of children with ASD (Roberts & Pickering, 2010), the program does not *specifically* target this area of need.

More recently, a new addition to the IY suite of parent programmes has been developed, entitled the IY-Autism Spectrum and Language Delays programme, IY-ASLD (Webster-Stratton, 2015). This specific programme was developed to help parents to promote their children's language and communication skills, emotional regulation, social competence, and their relationships with others. There are eight topics covered on the programme: child-directed narrated play; pre-academic and persistence coaching; social coaching; emotion coaching; developing imagination through pretend play; promoting children's self-regulation skills; using praise and rewards to motivate children; effective limit setting; and behaviour management.

The programme is recommended to be delivered in a minimum of 12 sessions and uses the same proven core methods of IY group delivery: group discussion; video-mediated learning of principles to be adapted for individual parents' home use; and practise of the strategies tailored for their individual child or children's needs. The emphasis is on development of the parent-child relationship and developmental outcomes such as communication skills, social and adaptive skills and reduction of behavioural problems. The importance of tailoring the programme to the needs of parents of children across the developmental spectrum of ASD is prioritised on the accredited training and reflected in the program manual and materials. The programme developer has recommended that group leaders are trained in the BASIC program and have experience of working with children with ASD.

The NHSCT Pilot project objective

The objective for this pilot programme was to assess its effectiveness at helping parents with children with ASD.

Advice on the screening process, including the suitability of parents for the programme was provided by the group leaders. The selection process was undertaken by staff from NHSCT. Inclusion criteria were as follows:

- Parents and/or caregivers of children recently diagnosed with ASD or awaiting assessment at diagnostic clinics;
- Children should be between the chronological ages of 2 and 5 (with extension to 7 years of age to take account of the presence of developmental delays);
- Parents' agreement that childcare would be possible to support them attending an introductory session and 12 subsequent weekly sessions on a Tuesday evening from 6-8.30pm.

9 parents commenced the 12 week programme, two of whom missed the introductory session provided by the group leaders one week before the programme started.

Participant information

The following table contains information regarding completion rates, attendance rates and number of targeted children for this treatment programme.

Number of	9
parents/caregivers/caregivers who	
commenced the programme	
Number of parents who completed the	8
programme	
Number of female participants	6
Number of male participants	2
Number of couples attending together	2
Number of targeted children with ASD	7
diagnoses	
Number of children awaiting ASD	2
assessment	
Total number of children	11
Overall attendance rate over 12 weeks	82%
Percentage of participants who had	50%
100% attendance over 12 weeks	

Group Leader Profile and Implementation fidelity

The skill level of group leaders running parent programmes has been found to be a significant predictor of programme effectiveness, with a major influence on child outcomes recorded (Scott, Carby and Rendu, 2008).

This programme was delivered by two very experienced group facilitators, one an Incredible Years® Mentor and the other an Accredited Incredible Years® Peer Coach:

- One of the group leaders is an Incredible Years® Mentor for the BASIC programme, a Senior Educational Psychologist and an Academic and Professional Tutor on the doctorate educational psychology course in the School of Psychology, Queen's University Belfast. Maria has delivered 12 Incredible Years® parent programmes to date and has supported 18 group leaders in NI to achieve their accreditation in the programme.
- The other group leader is an Accredited Incredible Years® Peer Coach and manager of Daisy Daycare Family Intervention Centre in West Belfast. Angela has delivered 12 parent programmes to date and provides peer coaching to numerous group leaders currently delivering parenting programmes in NI.
 Angela is the grandmother of 4 children with diagnoses of Autism Spectrum Disorder.

During this intervention programme, ensuring the delivery of a high quality programme and implementation fidelity was paramount. All sessions were recorded for supervision and evaluation purposes, with parental consent secured. The facilitators accessed support and supervision from the programme developer, Dr Carolyn Webster-Stratton, via skype consultation, which comprised video review and peer coaching for development of high quality group leader delivery skills. Both facilitators are working towards accreditation in the programme which will be completed by Dr Webster-Stratton, therefore every session was recorded in its entirety in preparation for sending for review for accreditation purposes.

Facilitators also completed self and peer evaluation checklists at the end of each group session, evidencing which session components were delivered during the session. Additional fidelity measures incorporated into this IY-ASLD programme were self and peer reflection on all delivery skills through completion of regular shared video reviews.

PART TWO: RESEARCH AND EVALUATION

Overall Research Aim:

To assess the effectiveness of the IY-ASLD programme at helping parents of children with ASD or awaiting ASD assessment within the NHSCT area.

Research Questions

In assessing the effectiveness of the IY-ASLD programme at helping parents of children with ASD in the NHSCT area, two specific research questions will be explored:

Research Question 1: Does the IY-ASLD programme show improvements on parental ratings of autism impact, parental stress levels, and children's behavioural difficulties at home?

Research Question 2: What are the participants' views and experiences of receiving this intervention, and what are the facilitators views?

Aim of Evaluation

The pilot is being evaluated by analysing pre and post standardised measures, including measures of the impact on autism, parental stress levels associated with parenting a child with Autism, and level of behavioural difficulties reported by parents. All of the outcomes of the various evaluation measures are intended to inform decisions about the appropriateness of the programme as a model of service delivery for supporting parents of children with ASD living in the NHSCT area.

Methodology

In terms of the methodology, a mixed-methods, sequential explanatory design was therefore used (Creswell & Clark, 2017). The quantitative strand used a pre-test, post-test design and qualitative measures were used to try to fully capture the experiences of participants.

Quantitative Measures

Incredible Years® *'built-in' measures* (refer to <u>www.incredibleyears.com</u> for more information)

As part of delivering a manualised programme, parents completed the Incredible Years program measurement tools. This comprised a session evaluation form at the end of each weekly session and a final satisfaction questionnaire at the end of the programme. Each week, facilitators made contact with each parent on the programme, completed 'buddy calls' to offer support and individual guidance, and to evaluate the success of the strategies on a weekly basis.

The Incredible Years® Autism Programme Weekly Evaluation Forms were completed by the participants at the end of every group session. The forms contain five items regarding the helpfulness of: (1) programme video clips, (2) group leader teaching, (3) group discussions, (4) the use of practice exercises, and (5) home activities. Responses are rated on a four-point scale, as either 'not helpful', 'neutral', 'helpful' or 'very helpful'.

The weekly evaluation forms also served the purpose of guiding the group facilitators in their planning, completing self and peer reflections and making subsequent step adjustments in their delivery styles and methods utilised.

Additional Measures used

A range of tools have been used to assess this new programme from the IY suite. For the purpose of this pilot, an exploratory use of four standardised measures is presented. These measures are among those recommended by the programme developer and have been used by Incredible Years® Trainer Judy Hutchings in Wales in her pilot research with this program.

The following quantitative measures were completed at pre and post programme stages by all parents/caregivers. Two couples attended the program, therefore 10 rating scales were completed in total. Eight subscales or sets of scores were analysed in total across the four measures:

- The Autism Impact Measure (AIM, Kanne et al, 2014) is a 25-item scale which reports frequency and impact of behaviours associated with autism. Symptom frequency is measured and symptom-related functional impact. The Autism Impact Scale is a reliable and valid measure targeting sensitivity to change of core ASD symptoms. The measurement properties of the AIM were chosen for its potential to provide clinically useful information about both frequency and impact of symptoms. Four component scores have been analysed for the purpose of this particular evaluation (Section 1 frequency, Section 1 impact, Section 2 frequency and Section 2 impact).
- The Autism Parenting Stress Index (Silva and Schalock, 2012). The Autism Parenting Stress Index (APSI) tool is a measure of parental stress as perceived by caregivers of young children with autism. It reflects the physical, social, and communication barriers imposed by the disability. As such, the items on this test fall into three categories: the core social disability; difficult-to-manage behaviour; and physical issues, with one total stress score generated. The test is designed to indicate how much stress parents are experiencing and what factors are causing this stress.
- Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997) is a 25 item scale that has five subscales: Emotional problems, Peer problems, Hyperactivity, Conduct problems and Pro-social behaviour, creating a 'Total difficulties' score. It has been used to screen for behaviour associated with conduct problems in many studies (Hutchings et al, 2007; Jones et al, 2008; Hutchings et al, 2011). Only the total difficulties score will be analysed for the purpose of this report.

• The Eyberg Child Behaviour Inventory (Eyberg,1999) is a comprehensive, behaviourally specific rating scale that assesses the current frequency and severity of disruptive behaviours in the home, as well as the extent to which parents find the behaviour troublesome. Both instruments consist of items that represent common behaviours in all children. The variety and frequency of these behaviours distinguishes 'normal' behaviour problems from conduct-disordered behaviour in children and adolescents. On the 36-item ECBI the parent indicates how often each behaviour currently occurs (7-point Intensity scale) and whether or not the behaviour is a problem (Yes/No Problem scale). Two sets of scores will be analysed for each participant: Eyberg Frequency and Eyberg Problems.

Qualitative Measures

A focus group interview with 7 out of the 8 parents was facilitated by a trainee educational psychologist at the end of the program. A series of semi-structured interview questions were administered. The interview was then transcribed by an administrative assistant and the data analysed. Dr Donncha Hanna, a senior quantitative researcher in the School of Psychology at Queen's University Belfast checked the data analysis procedures for accuracy.

Facilitators were also asked about their learning reflections at the end of the programme.

PART THREE: RESULTS

This section provides an account of the analyses of the quantitative and qualitative data gathered during this pilot project. Analyses of the exploratory use of the standardised measures is presented, including autism impact measurement, parental stress, and extent of behavioural difficulties at home. These are presented in tabular format. Analyses of the qualitative data is presented through a visual display of themes and subthemes followed by a narrative account with verbatim quotes highlighting themes. Both the quantitative and qualitative results are then integrated within a summary of the findings for each research question, which will then inform the discussion and conclusion section that follows.

Research Question 1: Does the IY-ASLD programme show improvements on parental ratings of autism impact, parental stress levels, and children's behavioural difficulties at home?

The results from the four aforementioned measures are considered in relation to this question, and results of analysis of the eight named components are now presented.

Paired t tests were used to compare scores for evidence of any statistically significant changes, using software known as the Statistical Package for the Social Sciences (SPSS). In addition to statistical significance, effect sizes were also calculated, namely 'Cohen's d' (Cohen, 1988). Presenting effect sizes allows us to move beyond the simplistic, 'Does it work or not?' to the more sophisticated, 'How well does it work in a range of contexts?'. Furthermore, by placing the emphasis on the most important aspect of an intervention, the size of the effect (rather than its statistical significance only) promotes a more scientific approach to the accumulation of knowledge. For these reasons, effect size is regarded as an important tool in reporting and interpreting effectiveness.

AUTISM IMPACT MEASURE

1. Autism Impact Measure: Section 1 Frequency
Parents completed this measure at pre and post program time points. This withinsubjects measure was analysed using paired t-tests. Results of the statistical
analysis of Section 1 Frequency are presented in Table 1 below.

Table 1: Participants' completion of AIM Section 1 Frequency (n=10)

				Paired Sar	mples Test				
					95% Confiden	ce Interval of the			Sig. (2-
			Std.	Std. Error	Diffe			tailed)	
		Mean	Deviation	Mean	Lower	Upper	t	df	p value
Pair	PRE -	9.60000	7.38166	2.33429	4.31948	14.88052	4.113	9	.003
1	POST								

Result

When comparing pre (T1) and post (T2) scores on the Autism Impact Measure Section 1 Frequency, the paired t test revealed a **statistically significant decrease** in the frequency of core ASD symptoms observed by parents at home (p<.05) with a **large** effect size (d = 0.8). This section asked parents to record the frequency of behaviours as observed *over the past 2 weeks*. Examples of behaviours assessed include: shown fascination with parts of objects rather than the whole toy; lines things up; resisted changes in routines; experienced problems in social interactions. A sample of the complete checklist which includes details of all questions is available from the authors of the report.

2. Autism Impact Measure: Section 1 Impact
Parents completed this measure at pre and post program time points. This measure
was analysed using paired t-tests. Results of the statistical analysis of Section 1
Impact are presented in Table 2 below.

Table 2: Participants' completion of AIM Section 1 Impact (n=10)

Paired Samples Test									
Paired Differences									
				95% Confide			Sig. (2-		
		Std.	Std. Error	of the Difference				tailed)	
	Mean	Deviation	Mean	Lower	Upper	t	df	p value	
PRE -	16.70000	8.08359	2.55626	10.91735	22.48265	6.533	9	.000	
POST									
	—	PRE - 16.70000	P Std. Mean Deviation PRE - 16.70000 8.08359	Paired Different Std. Std. Error Mean Deviation Mean PRE - 16.70000 8.08359 2.55626	Paired Differences 95% Confide Std. Std. Error of the Di Mean Deviation Mean Lower PRE - 16.70000 8.08359 2.55626 10.91735	Paired Differences 95% Confidence Interval Std. Std. Error of the Difference Mean Deviation Mean Lower Upper PRE - 16.70000 8.08359 2.55626 10.91735 22.48265	Paired Differences 95% Confidence Interval Std. Std. Error of the Difference	Paired Differences 95% Confidence Interval Std. Std. Error of the Difference	

Result

When comparing pre (T1) and post (T2) scores on the Autism Impact Measure Section 1 Impact, the paired t test revealed a **statistically significant decrease** in the reported impact of the frequency of core ASD symptoms observed by parents at home (p<.05) with a very **large** effect size (d = 1.56). This section asked parents to record how the impact of the behaviours of Section 1 interfered with the child's everyday functioning as observed *over the past 2 weeks*. Examples of impact measurement ranged from 'not at all' to 'severely' on a likert scale. A sample of the complete checklist which includes details of all questions is available from the authors of the report.

3. Autism Impact Measure: Section 2 Frequency
Parents completed this measure at pre and post program time points. This withinsubjects measure was analysed using paired t-tests. Results of the statistical
analysis of Section 2 Frequency are presented in Table 3 below.

Table 3: Participants completion of AIM Section 2 Frequency Results (n=10)

Paired Samples Test											
Paired Differences											
					95% Confide			Sig. (2-			
			Std.	Std. Error	of the Difference				tailed)		
		Mean	Deviation	Mean	Lower	Upper	t	df	p value		
Pair	PRE -	-	5.05085	1.59722	-5.81316	1.41316	-1.377	9	.202		
1	POST	2.20000									

Result

When comparing pre (T1) and post (T2) scores on the Autism Impact Measure Section 2 Frequency, the paired t test revealed that there was no statistically significant difference in the frequency of core ASD symptoms observed by parents at home on this scale (p=.20; p>.05). This section asked parents to record the frequency of behaviours as observed *over the past 2 weeks*. Examples of behaviours assessed include: held back and forth conversations; used a social smile to greet people or respond to them; comforted other when they were upset. The complete checklist which includes details of all questions is included in the appendix.

4. Autism Impact Measure: Section 2 Impact

Parents completed this measure at pre and post program time points. This measure was analysed using paired t-tests, each of the four component scales were analysed separately. Results of the statistical analysis of Section 2 Impact are presented in Table 4 below.

Paired Samples Test Paired Differences 95% Confidence Interval Sig. (2-Std. Std. Error of the Difference tailed) df Mean Deviation Mean Lower Upper p value Pair PRE -4.80000 5.71159 1.80616 .71418 8.88582 2.658 9 .026 POST

Table 4: Participants' completion of AIM Section 2 Impact (n=10)

Result

When comparing pre (T1) and post (T2) scores on the Autism Impact Measure Section 2 Impact, the paired t test revealed a **statistically significant decrease** in the reported impact of the frequency of core ASD symptoms observed by parents at home (p<.05) with a **large** effect size (d =0.8). This section asked parents to record how the impact of the behaviours of Section 2 interfered with the child's everyday functioning as observed *over the past 2 weeks*. Examples of impact measurement ranged from 'not at all' to 'severely' on a likert scale. A sample of the complete checklist which includes details of all questions is available from the authors of the report.

AUTISM PARENTING STRESS INDEX

Parents completed this measure at pre and post program time points. This measure was analysed using paired t-tests, with analysis of the total stress score generated. Results of the statistical analysis of the APSI are presented in Table 5 below.

Table 5: Participants' completion of the Autism Parenting Stress Index (n=10)

Paired Samples Test									
	Paired Differences								
					95% Confide			Sig. (2-	
			Std.	Std. Error	of the Difference				tailed)
		Mean	Deviation	Mean	Lower	Upper	t	df	p value
Pair	PRE -	9.30000	10.71914	3.38969	1.63199	16.96801	2.744	9	.023
1	POST								

Result

When comparing pre (T1) and post (T2) total stress scores on the Autism Parenting Stress Index, the paired t test revealed a **statistically significant decrease** in the total stress scores of parents (p<.05) with a **large** effect size (d =0.9). This section asked parents to rate aspects of their child's health according to how much stress it causes the parent and/or the family by indicating which description best described their situation (examples included aspects such as: 'your child's ability to communicate'; 'tantrums/meltdowns'; and 'self-injurious behaviour'). Stress ratings on a likert scale ranged from 'not stressful' to 'so stressful sometimes we feel we can't cope'. A sample of the complete checklist which includes details of all questions is available from the authors of the report.

STRENGTHS AND DIFFICULTIES QUESTIONNAIRE

Parents completed this measure at pre and post program time points. This measure was analysed using paired t-tests, with analysis of the 'total difficulties' score completed. Results of the statistical analysis of the SDQ are presented in Table 6 overleaf.

Table 6: Participants' completion of the SDQ Total Difficulties Score (n=10)

Sig. (2-
Sig. (2-
tailed)
p value
.176

Results

When comparing pre (T1) and post (T2) scores on the SDQ 'Total difficulties', the paired t test revealed that there was no statistically significant difference in the total difficulties recorded as observed by parents at home on this scale (p=.17; p>.05).

EYBERG CHILD BEHAVIOUR INVENTORY

1. Eyberg Frequency or Intensity of behaviours: Parents completed this measure at pre and post program timepoints. On the 36-item ECBI the parent indicates how often each behaviour currently occurs on a 7-point Intensity likert-type scale (1 indicates 'never' through to 7 which indicates 'always'). Examples of questions include: refuses to go to bed on time; gets angry when doesn't get own way; acts defiant when told to do something. The results are presented in table 7 below.

Table 7: Participants' completion of the Eyberg Child Behaviour Inventory: Frequency of Behaviour Scale (n=10)

			Pai	red Sampl	es Test				
					95% Confide			Sig. (2-	
			Std.	Std. Error	of the Difference				tailed)
		Mean	Deviation	Mean	Lower	Upper	t	df	p value
Pair	PRE -	.20000	43.21471	13.66569	-30.71394	31.11394	.015	9	.989
1	POST								

Results

When comparing pre (T1) and post (T2) scores on the ECBI Frequency scale, the paired t test revealed that there was no statistically significant difference frequency of

behavioural difficulties recorded as observed by parents at home on this scale (p=.98; p>.05).

2. Eyberg Problems: Parents completed this measure at pre and post program timepoints. On the 36-item ECBI the parent indicates how problematic certain behaviours are at home, by circling either 'Yes' or 'No' to the question 'Is this a problem for you?' The results are presented in table 8 below.

Table 8: Participants' completion of the Eyberg Child Behaviour Inventory: Problem Scale (n=10)

Paired Samples Test									
	Paired Differences								
					95% Confide			Sig. (2-	
			Std.	Std. Error	of the Difference				tailed)
		Mean	Deviation	Mean	Lower	Upper	t	df	p value
Pair	PRE -	5.50000	6.85160	2.16667	.59866	10.40134	2.538	9	.032
1	POST								
ì									

Result

When comparing pre (T1) and post (T2) problem scores on the Eyberg Problem Scale, paired t tests revealed a **statistically significant decrease** in scores between the two time points (p<.05) with a **medium** effect size (d=0.7). A sample of the complete checklist which includes details of all questions is available from the authors of the report.

Research Question 2: What are the participants' views and experiences of receiving this intervention? Secondly, what are the facilitators views?

The results from two sets of data are considered in relation to the participants' views: analysis of weekly session evaluation forms from all twelve sessions (completed individually by the participants); and analysis of the focus group interview with 7 out of 8 parents who completed the programme.

The facilitators' reflections are included at the end of the section.

1. ANALYSIS OF WEEKLY EVALUATION FORMS

The figures that follow provide pictorial representation of participants' evaluations of all parts of the sessions during the programme. Ratings of five aspects of the session are required to be completed by participants at the end of each session: 'Vignettes' (vignettes are simply video clips of parents and children with ASD interacting) and content; Group Leaders' teaching and leadership skill; Group discussion and Interaction; The use of practise exercises (or 'practising' the new strategy in the session, pretending to be using it at home with their child); and home activities and reading. A likert scale is used with ratings available as follows: not helpful; neutral; helpful; and very helpful.

Figure 1 overleaf shows the percentages of parents' weekly ratings on watching the vignettes and assessing programme content over the course of the 12 week programme. Results indicate that 99% of the parents rated the vignettes and their learning content as helpful, indicating a very high level of satisfaction with this component. Group delivery involves asking the manual based questions after each vignette, with opportunities to tailor the learning to any parent's individual child.

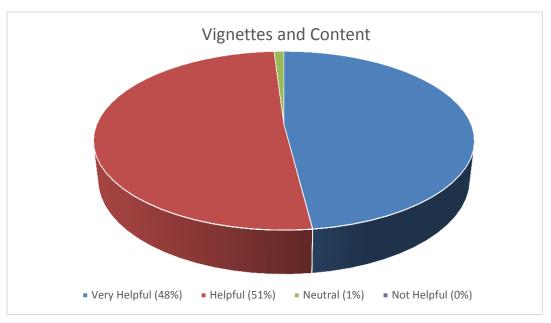
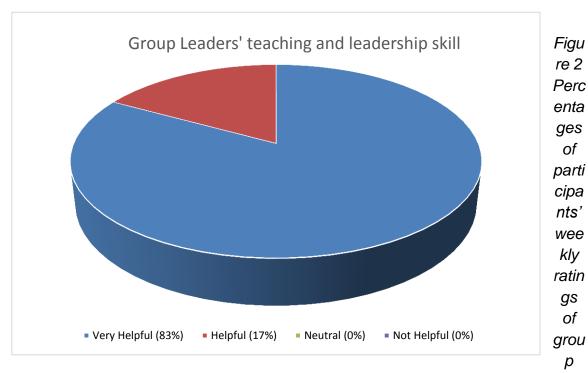


Figure 1 Percentages of Participants' weekly ratings on vignettes and content



leader teaching and leadership skill

Results from parents' ratings of group leader teaching and leadership skill are depicted in Figure 2 above. The findings indicate that 100% of parents rated the group leaders' skill levels as either helpful or very helpful over the course of the program. This is an extremely high level of satisfaction with the group leaders and their delivery of this 12 week programme. The programme is delivered by two group

leaders, working collaboratively as a team, sharing delivery all aspects of the session content. This collaboration is an essential component of IY delivery, promoting a model of equal status and cooperation between group leaders who model positive communication and interaction styles.

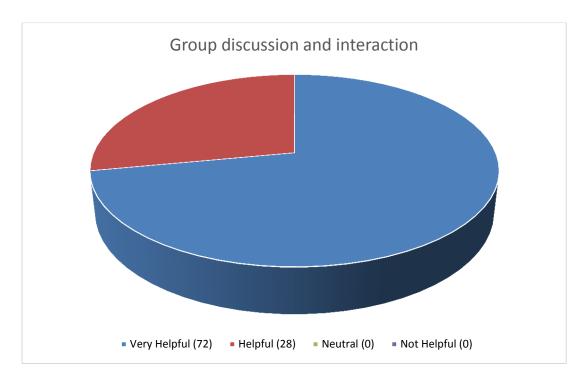


Figure 3 Percentages of participants' weekly ratings on group discussion and interaction

Results of the analysis of parent ratings throughout the program on group discussion and interaction are displayed above in Figure 3. Findings indicate that 100% of parental ratings of this component were either helpful or very helpful indicating an extremely high level of satisfaction with this aspect of the programme. Group interaction and discussion is an essential element of delivery of a programme with a collaborative approach. The emphasis is on parents engaging with the material, discussing it, learning from it, and interacting with each other through vignette discussion, sharing of home practise activities, having a go at practising the strategies suggested, and talking about their individual children with ASD.

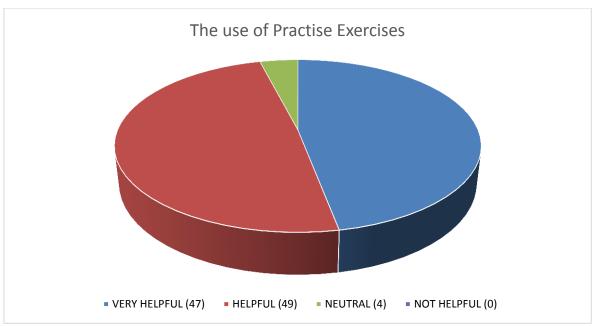


Figure 4 Percentages of parents' weekly ratings on use of practise activities

As part of this IY-ASLD program, parents are supported to practise the new strategies during the session so that they are equipped to use them at home that week with their children with ASD. Results are shown in Figure 4 above, detailing that 96% of the parents' weekly ratings were either helpful or very helpful for this component of the programme, indicating a very high level of satisfaction with this element. The program is individually tailored so that practises are suited to the developmental needs of each parent's child, with specific adjustments made to the practise to accommodate for developmental differences such as language, communication and interactional levels, sensory needs, play level and pretend play skill level. Parents are supported by the group leaders to 'step out of their comfort zones' in order to practise the skills in front of the whole group to aid everyone's understanding and in smaller dyads or pairs.

Figure 5 overleaf presents the analysis of weekly ratings over the course of the programme for the handouts including notes, practical ideas and reading material. Results indicate a very high level of satisfaction with this component; 97% of parents' ratings over the course of the program were either helpful or very helpful. The weekly written activities consisted of record keeping, key concepts and reflection aides. Parents were also given their own copy of the book entitled 'The Incredible Years, A troubleshooting Guide for parents of children aged 2-8' by Dr Carolyn Webster-Stratton. This book offers support, guidance and practical consolidation of most of the content covered during the program. Home activities include the reading of certain chapters of the book and parents are asked about their experience with the previous week's strategies at the start of each session.

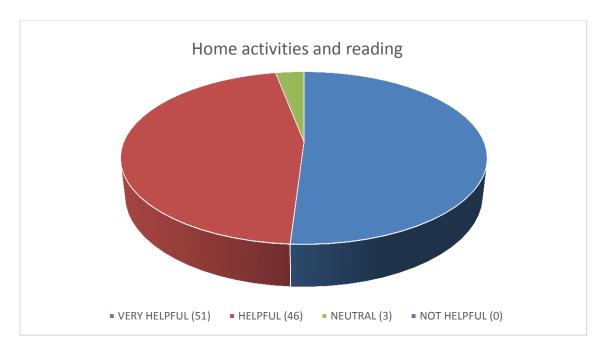


Figure 5 Percentages of parents' weekly ratings on written handouts and reading

2. ANALYSIS OF THE FOCUS GROUP INTERVIEW

A focus group interview was organised to ascertain the views and experiences of the participants completing the IY-ASLD parent programme. The focus group interview was facilitated by a trainee Educational Psychologist who had no involvement with the programme. A thematic analysis of the responses of the participants on their experiences of the programme was conducted. The four main themes which emerged from participant accounts are presented in Figure 6 overleaf.

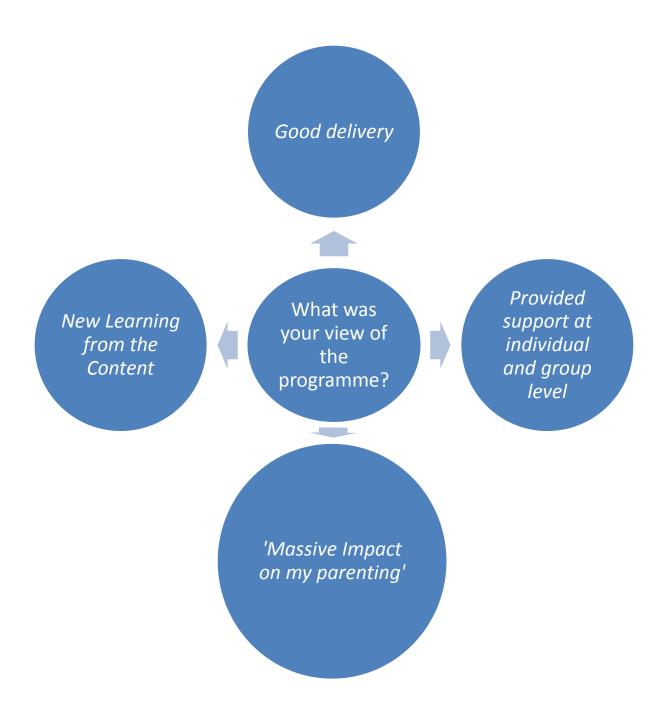


Figure 6: The four main themes from Participants' on their views of the programme

Thematic Analysis of the IY-ASLD focus group interview

Focus group participants reported hugely positive experiences of the programme. Two overarching themes emerged from the findings: what participants deemed to be effective; and what improvements they would suggest for the programme.

Theme 1: Effectiveness of the programme

As shown in figure 6, four main themes emerged from participants' views of the effectiveness of this programme:

- 1. The Content of the Programme;
- 2. The Delivery of the programme;
- 3. The Support provided;
- 4. Impact on parenting skills.

These themes will now be presented in detail and some subthemes highlighted where appropriate.

1.Content

Participants commented on how the Content of the programme was effective in terms of the new learning it provided. The following are quotes from participants attending the focus group interview.

Participants commented on the *new learning* gained from the content of the program:

'the girls said that eye contact was important, and shared information about why and said you know here's what you can do, so it helped you identify what things you should sort of push and try and work with, rather than you know just helping your child cope in the world';

"I liked the attention spotlight because I used to struggle actually getting attention and I would try and force her to look at me, look at me, or it would be a constant struggle whereas the attention spotlight almost seems like second nature now, I'll start playing with a toy, she'll see what I'm playing with and then a conversation and it seemed almost a lightbulb moment when I've seen it on videos, like why didn't I think of that? You know so I thought it was really good'; (male participant)

'I never would have thought of social coaching before and I maybe would have done it without really labelling it, I'm more aware of that, thinking right I am struggling in this area how could I use a bit of social coaching';

'it gave you tools to equip you to know what to work on and know when to just let go';

'I definitely think the course has taught you, in that, does this behaviour matter you know, or is it a bad behaviour, or is it a behaviour the child can't control. I think the strategies on this course help you understand why children behave that way';

'you're so emotionally drained because you can't understand the behaviour, yes it might be challenging behaviour but you're actually aware now of how to use the strategies, and reasons for the behaviour'.

2.Delivery of the programme.

Participants commented on how the delivery of the programme was effective. These comments are presented with reference to three subthemes within this component:

- a. Delivery Approach;
- b. Delivery Methods;
- c. Group Leader level of skill.

The following are quotes from participants attending the focus group interview.

a.Participants commented on how the programme was effective in terms of the delivery approach of the program:

'this programme focuses on the strengths of your child rather than you know 'your child can't socialise very well';

'I liked the way it was split up into different topics';

'the facilitators would definitely always find ways to meet your child's needs. They would phone or text you and you know arrange a convenient time that they could check in with you and see how you are getting on with it';

'this programme really focuses on the whole of your child. Autism is a part of your child or whatever you know diagnosis they have but I think it definitely focuses on you, your child and how you can meet their needs and what the programme can do to help you';

'one of the first things we did on the course was put the child's name on the whiteboard so everyone could see the names of the children and what their interests are and say the same for their diagnosis. You are able to see then that they are humans with likes and dislikes as opposed to just a diagnosis'. (male participant).

b.Participants commented on how the programme was effective in reference to the Delivery Methods used in the program:

'I felt a bit cringey taking stickers for the right answers and stuff but now I've got to the end of the course I can actually see that, that it's been teaching me the whole time of how to act like that with my child, praising the kids, you're not used to people being like that';

'I personally in life don't really find role play that helpful, but it was helpful you know, if you'd said my daughter does this and when I tried to help her she does this and this happens, 'Ok let's role play it as a group and figure out what we could do', and that was a useful way to use role play as well';

'they would have prompted me which then made me feel more comfortable and confident to go home and try it';

'at times you felt a bit daft and there were times you felt what on earth am I doing this for but when you came to try it out with your kids you realised that it did actually help';

'the videos were good but the discussions were more valuable';

'I did feel like I'm being told I have to do this in this way but I'm not comfortable doing that but I did realise after a couple of weeks that I don't have to, it's just sort of ideas in the vignettes for how to get to the means to an end'.

c.Group Leader level of skill. Participants commented on how effective the programme was with reference to the level of skill demonstrated by the two group leaders:

'I have to be honest I think Maria and Angela, it's very obvious that it's not just a job and they're not just gonna stand there and do a course, they are so passionate about what they do and they are so passionate about finding an option. Angela and Maria were always keen to work with you to find how, they always tried to find an alternative, always encouraging you even though you thought a strategy didn't particularly work';

'it's been the personable nature of the facilitators, just them practically knowing your children, without actually seeing them and showing interest that's probably the first thing we've experienced that somebody who is not related to you who actually cares, they are actually interested in you, and your kids, it's just really, really nice; (male)

'you know they really did facilitate it really well and were really really helpful';

'you weren't just a number';

'the facilitators were always finding a way to meet your child's needs';

'I would trust them and have a lot of confidence in them';

'they definitely knew what they were doing';

'they just never looked like they didn't know an answer';

'nothing we were asking was too much';

'nothing was shocking and nothing got them in a flap'.

3.Support from the programme.

Participants commented on how the programme was effective in terms of the support provided. Analysis of these comments is presented with reference to two subthemes within this component:

Participants commented on how the support provided was effective in terms of:

- a. Support provided at the individual and the group level;
- b. Support provided in comparison to other previously attended events.
- a. Support provided at the individual parent level and the benefits of group support. The following comments were provided on how participants accessed support at both of these levels during the program:

'he has been diagnosed with ASD during the program so it's all been very new';

'there's a lot of people going through the very same things as I have';

'when you come here and between talking to everyone else and realising your kids are not so hard as ours, it normalises it, you know the way the vignettes are based and you realise this is just normal life';

'you hit a brick wall and you get so emotional, so emotionally drained because you don't understand the behaviour';

'normally I would have given up but you come back and get feedback and then say 'oh no that's totally normal';

'I'm pretty much a single parent, and it was nice that he could come, when he came the first night they encouraged him to keep coming';

'this programme focuses on the strengths of your child, and it has given us hope';

'the support network has been great, everyone kind of, we all kind of reflect and give each other advice in a positive way' 'I think one of the reasons why it has worked so well is it has been a nice small group'.

b.Participants commented on how they rated the effectiveness of this programme in comparison with support provided by previously attended events for parents with children with ASD. Participant quotes are as follows:

'anything we've had since the diagnosis and before has just been clinical spiel that you get';

'this is definitely geared towards people with kids on the Spectrum of any kind of difficulty and that is massive because going on training for parenting of mainstream kids is just so different than trying to parent children on the spectrum with behavioural difficulties';

'we felt we had tried everything and we weren't getting anywhere';

'If you can skip going to one of those one day ones and commit yourself to the weeks of doing this one, I think there is just so much benefit to it to this than there is going to days here and there';

'You go to the different training sessions and it's all just sitting in a lecture room and people talking about what Autism is';

'I went on a course at the trust and I left so downhearted and so frustrated and everyone who was there left in the same way, the facilitator herself was trying her best but she didn't have the strategies that Incredible Years has to put in place';

'most of the courses you go to you are one of how many people';

'Yeah in a large group, in a lecture hall, and you don't have the opportunities';

'Most of the courses run by the trust are one day and I think part of the benefits of this course is that it is over a period of time, and if you're not sure you have Maria and Angela to contact during the week, you learn something every week, you've got the book to go back to, you've got next week they ask you how you got on, if it was difficult, and also hearing how everyone else got on';

'remember last year that I went to a course that I paid to go to and we ended up having a revolt against the wee girl taking it, it wasn't ASD specific, sort of it ended up completely running away with her';

'I don't really believe there is very much early intervention that can be found and it's not accessible if it is there'; 'there's a lot of information thrown at you very quickly';

'You know the way the vignettes are based and you realise hold on this is just normal life. And there's a lot of people going through the same things as I have'.

4.Impact on parenting skills.

Participants on the programme commented on how the programme was effective in terms of its impact on their own personal parenting skills. Participants' comments were as follows:

'my relationship with my daughter has improved massively from the programme. I'm definitely a better parent than what I was before I started the course';

'it has improved my parenting skills I'd say immensely, you know it's given me a chance to stop and take a moment, not to force her to do things she doesn't want to do, because we have talked about things like attention spotlighting, and child directed play, play with her when she wants to play, give her a guide plan, give her a gentle push towards the way that would be beneficial for her'; (male participant)

'I wouldn't say it's been revolutionary for me but it has been beneficial'; (male participant)

'I'm just maybe fully more conscious about how I'm parenting and the decisions I make and the reactions that I have to certain situations, I've been putting more thought into it, there are some strategies that are new aswell so looking forward to keeping on using those';

'It helps with your confidence as a parent a lot';

'it has made me look at myself as a parent as well the way I react to my daughter, I think I've changed';

'I'm not going to say it's revolutionary, dramatic, you know my child is not fixed for want of you know a term, she definitely has the same struggles as she had before but now I have the strategies to be able to help her cope with situations. We still have the meltdowns but now I have the tools that I can help her cope better, and I'm definitely coping better';

'It has helped us bond in a way that she definitely trusts me more to be able to help her and she sees me as a crutch rather than before, perhaps, I maybe wasn't am, helping her in the way that she needed, I wasn't meeting her needs, through kinda no fault of her own but just without having those strategies and the knowledge so I definitely think that has helped us bond and definitely I think the strategies work, the strategies that you can use life long for her':

'I definitely feel like I'm more positive with my child, even when faced with adverse situations, I dealt with a tantrum where it worked out quite well'.

Theme 2: Participants' suggestions for improvement

Participants made a small number of comments on how they would improve the programme, comments are as follows:

'I definitely think the programme could run for longer perhaps even 16 weeks that kinda means you get a wee bit longer to implement the strategies, but you could also come back and reflect on them, but maybe things could be a slightly slower pace because there is so much you could go through';

'the name of the course, my daughter has zero speech and language delay, so I think if it was just called Incredible Years';

'my wee girl is six she did have language delays and she's got learning difficulties but I think this would have been more beneficial to me if she had been a little younger';

'there needs to be that initial kind of finding out about your kids cause when I think of the parent who came to the course and both her boys were non-verbal, both in pull-ups during the day, really severely delayed, there was more that was appropriate for us, most of our kids are at a similarish level'.

One participant's text message sent to both facilitators on 27.3.18, after Session 9:

I just want to say a massive thank you to both of you Angela and Maria for the genuine time, effort and passion you both have towards helping find strategies to improve mine & more importantly (child)'s life too. You both do really give so much support not just to myself but to the group as a whole each and every week. The incredible years course honestly isn't like any other course I've been on before and I've been on many many courses both personally and for work. You are two extremely passionate ladies & im so grateful for all the help & support you give.

I've honestly had a rough week with (child) regressing quite a bit after sickness and group tonight lifted a weight off my shoulders so thank you both!!

Facilitators' learning reflections

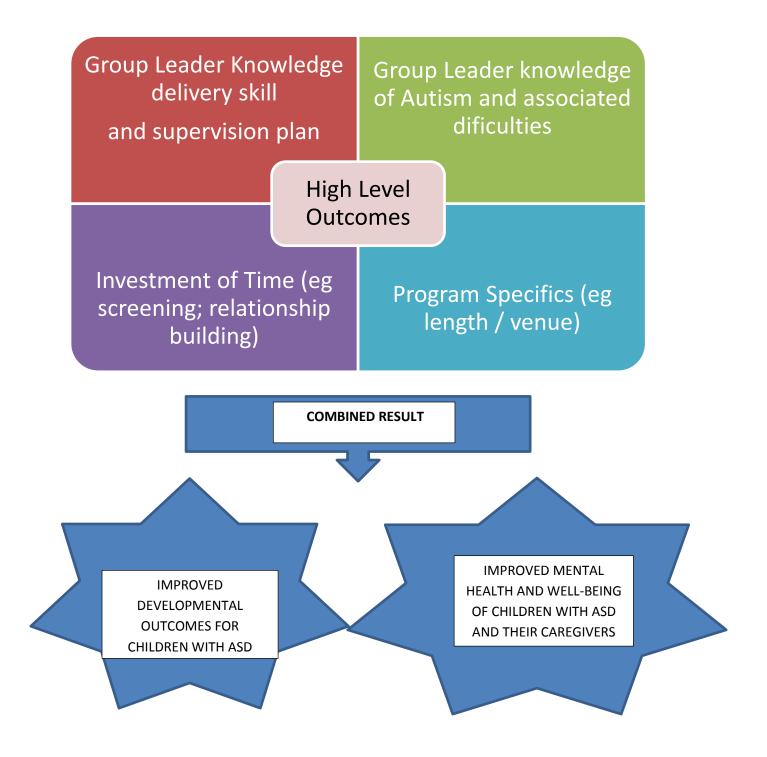
The facilitators expressed the following learning outcomes from delivering the programme:

- Both facilitators reported how much they loved delivering this programme for the NHSCT area. Both have learned so much, used self and peer reflection on so many skills, and improved their delivery of the programme throughout the 12 weeks;
- NHSCT staff were exemplary in their efforts to recruit parents and to support programme delivery. The venue provided superb hospitality, which was welcomed by both participants and facilitators on so many cold evenings during the programme!;
- Both the facilitators felt that the IY-ASLD programme was phenomenally successful at supporting NHSCT parents of children on the Autism Spectrum in terms of the relevance of its content, the suitability of its delivery methods and the extremely high degree of support it offers parents over a 3 ½ month period. In addition to the quantitative and qualitative research methods which have provided evidence of this, the weekly positive comments from participants during homework feedback (and during weekly 'buddy calls') provided ongoing testimony to the participants' practical application of the learning and strategies of the programme with their children at home;
- To echo the view of one of the parents who said 'I definitely think the programme could run for longer, perhaps even 16 weeks', both facilitators felt that the programme should be delivered with fidelity over a longer period than the minimum 12 weeks. In conjunction with learning derived from supervision provided by the programme developer, the facilitators' reflected on the high level of need in the group and that a longer programme (preferably 14-15 weeks) would allow more time for processing of the learning and help ensure fuller coverage of programme content;
- All participants who attended the introductory session before the programme commenced completed the programme. Having adequate time to nurture positive relationships with individual participants is one of the key factors in ensuring successful attendance and completion rates;
- The application of well-defined screening criteria helps ensure the suitability of the participants enrolled on the programme;
- Delivering this treatment programme to parents and caregivers of children
 with Autism was a challenging task. Substantial prior experience in delivering
 the Incredible Years® BASIC Parent Program (and being accredited in this
 program) proved invaluable. Accessing Incredible Years® supervision through
 peer coaching and working towards accreditation in this programme helped to
 ensure high quality standards were adhered to at all times and
 implementation fidelity was guaranteed;
- A very significant number of participants on the program reported a high level of challenging and behavioural difficulties presented by children at home.
 These difficulties were in association with or in addition to the Autism

- Spectrum difficulties reported. The facilitators' experiences and knowledge of supporting parents with managing their children's significant behavioural difficulties proved invaluable;
- It is a possibility that parents attending a programme such as this might be on the Autistic Spectrum themselves and/or present with comorbid conditions and/or learning difficulties. The facilitators continually reflected on the potential impact of such a possibility, and adjusted plans to support parents accordingly throughout the programme;
- Delivery provided in a venue that is some distance away from parents' homes, with no childcare facilities has potential impact on attendance rates.
 Notwithstanding this challenge, it was noteworthy that 50% of the parents attended 100% of the sessions delivered by the two appropriately qualified and experienced facilitators.

Summary of facilitators' reflections and learning

This report highlights extremely positive results for this particular IY-ASLD programme delivered for NHSCT. Figure 7 below depicts a 'take away' message for future delivery of similarly high quality, evidence based IY-ASLD programmes that will result in increased outcomes for children on the Autism spectrum, and their caregivers.



PART FOUR: DISCUSSION AND CONCLUSION

Introduction

The research questions were influenced by a pragmatist approach to consider the effectiveness of this programme, which led the way to both quantitative and qualitative measures being utilised. Using this mixed methods approach, a 'richer' picture is indeed presented, which will help inform the report's conclusions.

Research Question 1

The first research question looked to the heart of this pilot project to examine the effectiveness of the program by analysing quantitative data captured at pre and post programme time points. As the IY-ASLD programme is in its infancy both in terms of its development and its research profile, this pilot aimed to demonstrate an exploratory use of four standardised measures to help inform their fitness for purpose for this task. With the knowledge that it can be challenging to find appropriate measures which are sensitive to change over the course of a 12 week programme and are suited to the purpose of evaluating a parent programme for children with ASD based on parents' self-ratings, the pilot proceeded with exploratory use of these four measures.

As aforementioned, quantitative measures were explored for this pilot to evaluate programme effectiveness (Autism Impact Measure; Autism Parenting Stress Index; Strengths and Difficulties Questionnaire; and Eyberg Child Behaviour Inventory) alongside the inbuilt weekly session evaluations provided by participants. In terms of the additional measures, participants' pre/post ratings on eight scales or subsets were analysed for the purpose of this pilot.

Results showed that when pre and post results were compared on **five out of eight** measures, changes occurred at **statistically significant** levels (namely the AIM Section 1 Frequency, AIM Section 1 Impact, AIM Section 2 Impact, Autism Parenting Stress Index and the Eyberg Problem Scale). Four out of five demonstrated **large effect** sizes, one of which was 'very large' and one analysed as having a **medium effect** size (namely the Eyberg Problem Scale).

It is particularly noteworthy that the two Autism specific measures that were utilised showed such extremely positive results. The results gained from the Eyberg Problem Scale were also very promising, with parents' ratings of the 'degree of problems' associated with their children's behavioural difficulties at home *lowering significantly* by the end of the program.

In relation to research question 1, the evidence from the quantitative data presented in this report suggests that the IY-ASLD programme is extremely effective, as rated by participants completing the programme. The programme demonstrated statistically significant improvements (with large effect sizes) across a number of parental ratings of the impact of autism and the extent of this impact on the child's functioning. Statistically significant decreases in parental stress levels (again with a large effect size) are testimony to how the programme can help lower caregivers'

stress levels, improving their mental health and well-being. In addition, comparison of pre and post programme ratings of how problematic children's behavioural difficulties are at home showed statistically significant levels of change (with a medium effect size).

Future research

Notwithstanding the significance of the results on five of the eight pre/post scores analysed, the authors of the report are interested in continuing to reflect upon the factors contributing to non-significant scores on some of the measures and indeed whether any alternative measures would be suitable for future use. Additional evaluation of children's language skill development and alternative measures of, for example, social communication and/or social responsiveness could be explored. Additional measures charting other participant attitudinal changes would be interesting to explore (examples could include the caregiver's understanding of Autism, its core impairments and associated difficulties), and/or exploration of the occurrence or otherwise of difficulties experienced by caregivers (for example, adult presentations of ASD) and its effects on child outcomes, and/or any changes in family dynamics or relationships with partners over the course of the programme.

Research Question 2

The second research question explored the views and experiences of the participants on the programme by two methods: analysis of weekly session evaluation forms; and completion of a focus group interview to elicit participants' views and experiences of the programme as a whole.

The views of the two facilitators were also included in this report.

In terms of the Incredible Years® built-in measures, namely the complete set of parental session evaluations, exceptionally positive ratings have emerged. Results indicated extremely high levels of satisfaction with all the parts of programme content:

- 99% of the parents rated the vignettes and their learning content as 'helpful' or 'very helpful';
- 100% of parents rated the group leaders' skill levels as either 'helpful' or 'very helpful' indicating an extremely high level of satisfaction with this aspect of the programme;
- 100% of parental ratings of group discussion and interaction were either 'helpful' or 'very helpful' indicating an extremely high level of satisfaction with this aspect of the programme;
- 96% of the parents' weekly ratings for practise activities were deemed either 'helpful' or 'very helpful';
- 97% of parents' ratings of home activities and reading over the course of the program were rated as either 'helpful' or 'very helpful'.

Regarding the outcome of the focus group interview, the findings revealed that comments on the programme's effectiveness made during the interview ranged

across five separate domains: the *new learning* gained from the content of the program; how the programme was *delivered*; the *support* it provided; and the *impact* it had on the participants' own parenting skills. Very powerful reflections were provided by the participants as testimony to the strength of the programme, as detailed in the results section. Some of the very many favourable quotes included the following:

'the girls said that eye contact was important, and shared information about why and said you know here's what you can do, so it helped you identify what things you should sort of push and try and work with rather than you know just helping your child cope in the world'; (new learning)

'this programme really focuses on the whole of your child. Autism is a part of your child or whatever you know diagnosis they have but I think it definitely focuses on you, your child and how you can meet their needs and what the programme can do to help you'; (delivery approach)

'they would have prompted me which then made me feel more comfortable and confident to go home and try it' (delivery method)

'I have to be honest I think Maria and Angela, it's very obvious that it's not just a job and they're not just gonna stand there and do a course, they are so passionate about what they do and they are so passionate about finding an option. Angela and Maria were always keen to work with you to find how, they always tried to find an alternative, always encouraging you even though even if you thought a strategy didn't particularly work'; (group leader skill)

'when you come here and between talking to everyone else and realising your kids are not so hard as ours, it normalises it, you know the way the vignettes are based and you realise this is just normal life'; (support)

'Most of the courses run by the trust are one day and I think part of the benefits of this course is that it is over a period of time, and if you're not sure you have Maria and Angela to contact during the week, you learn something every week, you've got the book to go back to, you've got next week they ask you how you got on, if it was difficult, and also hearing how everyone else got on'; (strength of this particular programme)

'my relationship with my daughter has improved massively from the programme. I'm definitely a better parent than what I was before I started the course'. (impact on parenting skills)

A significant thread across all of the above five domains was the participants' continued emphasis on the fact that this treatment programme was **tailored to their child's individual needs**. This recurring theme was also communicated through

informal chats at session breaktimes with the leaders and through buddy contacts with participants. Participant quotes truly captured the importance of this aspect of the programme leaving us little doubt about its effectiveness for them:

This programme really focuses on the whole of your child The facilitators would definitely always find ways to meet your child's needs It definitely focuses on you, your child and what the programme can do to help you They are actually interested in you, and your kids, it's just really, really nice This programme focuses on the strengths of your child, and it has given us hope

In terms of the participants' reflections on what could be improved, it was interesting to note that these referred to more systemic aspects, reflecting the participants' high level of regard for the programme itself (adding more sessions, starting the programme when your child is younger than 6, initial screening procedure improvement, and reflection on the name of the programme).

The facilitators *highly valued* the programme too, in terms of its content and role in supporting parents of children with ASD. Their main learning reflections centred upon: the need for continued development of screening procedures; the importance of maximising opportunities to build relationships with parents prior to programme delivery; and the importance of continued reflection, learning and self and peer evaluation. The tremendous success of the programme was undoubtedly an effective combination of many factors, including the high level of skill demonstrated by the group leaders, which undoubtedly helped to secure such extremely positive results. Both were suitably experienced in Incredible Years® parent programme delivery methods and group process skills, and in addition have an advanced level of knowledge of all of the potential difficulties and associated difficulties experienced by children on the Autism spectrum.

Limitations of the research

The following limitations of this research report are acknowledged:

- Small sample size for the quantitative measures affecting the results and evaluation of such results. To address this limitation in part, the authors of the report will be combining the data for this programme, one other programme they have delivered to date, and possible future programmes for evaluation and research publication purposes;
- 2. Short term timescale for the project limits potential for follow up work to be completed to assess the long term impact of the programme;
- Future research of the programme should try to limit biases such as social desirability bias and response-shift bias which can be at play using these research methods.

Conclusion

The overall research aim of this report was to assess the effectiveness of the IY-ASLD programme at helping parents of children with ASD within the NHSCT area. Results from both quantitative and qualitative elements provided very strong evidence of effectiveness, highlighting its cost effectiveness as a programme which offers substantial support to parents of children with ASD over a 3 ½ month period.

Research question one was answered with overwhelmingly positive results; improvements were indeed shown on parental ratings of autism impact, parental stress levels associated with parenting a child with Autism, and the level of behavioural difficulties reported by parents. On five out of eight measures, the differences between pre and post program scores were occurring at highly statistically significant levels, with four of the five having large effect sizes.

In seeking to address research question two, the participants' views and experiences of the programme were examined. The participants rated all aspects of the programme content and its format tremendously positively (percentages of satisfaction with each individual element rated as 'helpful' or above ranged from 96-100%). During the focus group interview, participants highlighted their high levels of satisfaction with the programme in terms of: its content and new learning; all of the delivery aspects including methods, approach and high level of group leader skill; the support it provided both at individual and group level; its standalone effectiveness compared to previous training they had ever accessed; and the very positive overall impact it has had on their own parenting skills. The facilitators highlighted how much they loved delivering this relatively new IY-ASLD programme for the NHSCT area. The facilitators have learned about improving and enhancing their abilities to deliver this challenging treatment programme in order to secure continued positive outcomes for children with ASD and their parents and caregivers.

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