

Incredible Years® Autism Spectrum Parent Programme:

Pilot Study

Powys

2015-2017

Introduction

The Incredible Years® Autism Spectrum and Language Delays programme was developed by Professor Carolyn Webster-Stratton in 2014 as an additional and targeted programme in the Incredible Years® Suite of programmes for parents, teachers and children. This programme has been piloted in Powys since autumn 2015. There was already a strong Incredible Years® strategy in Powys with a range of IY parent groups delivered annually through Action for Children, commissioned providers of parenting, and a range of partner agencies. In addition the majority of primary schools in Powys have staff trained in the IY Teacher Classroom Management and Classroom Dinosaur Programmes and many Early Year setting staff have received IY training.

The Strategic Parenting Forum in Powys identified specific parenting programmes for parents of children with autism as a gap in provision and strongly supported the piloting of the IY Autism programme.

The IY Autism Spectrum programme is designed to be delivered in 12 weekly, two-hour sessions. It is intended for parents of young children (aged 2-5 years) who have been diagnosed with autism and/or with language delay, but is currently being researched in Wales with children up to 8 years of age who have a diagnosis of autism or where autism is strongly suspected. There are eight topics:

1. child-directed narrated play
2. pre-academic and persistence coaching
3. social coaching
4. emotion coaching
5. developing imagination through pretend play
6. promoting children's self-regulation skills
7. using praise and rewards to motivate children
8. Effective limit setting and behaviour management

The programme uses a collaborative approach, encouraging parents to learn from each other. Methods used include role-play skills practices, modelling, group discussion, home activities and reviewing DVDs of family situations that include examples of parents with children on the autism spectrum.

The IY Autism groups in Powys have been coordinated by Action for Children as commissioned providers of parenting, but delivered solely by staff from partner agencies who are Autism specialists. Staff delivering include:

- Specialist Speech and Language Therapist
- Learning Disability Nurses
- Specialist Learning Disability Well Being Officers
- Educational Psychologists
- Clinical psychologists
- Specialist Teachers

In Powys we have a Consultant Child Psychologist who is the only accredited Trainer in the IY Autism programme in the UK. As a consequence it has been possible to build a supportive infra structure for training and supervision which is likely to have contributed to the excellent outcomes illustrated below. Two trainings for group leaders have been delivered and a total of 32 leaders have been trained. In practice only autism specialist will be delivering this programme, but many generic staff from the Family and Behaviour Support Service have received the training in order to raise their awareness of the programme and how it supports parents.

All of the five groups included in this evaluation were delivered by Autism specialists, all groups were videoed and leaders received regular supervision through video review from the local accredited trainer.

This brief report presents an analysis of outcomes from the IY Autism groups that were completed between September 2015 and June 2017.

Partnership in Research

We are currently partnering in a randomised control, trial with Bangor University which is examining the feasibility of delivery of the IY Autism programme and the effectiveness of the programme. The protocol paper for this study can be found at:

Williams, M.E., Hastings, R.P., Charles, J.M., Evans, S., & Hutchings, J. (2017). Parenting for Autism, Language, And Communication Evaluation Study (PALACES): protocol for a pilot randomised controlled trial. *BMJ Open*, e014524. doi:10.1136/bmjopen-2016-014524

The current evaluation does not have access to a group of parents who have not received the intervention for the purposes of comparison. Involvement in the above randomised control trial will provide additional robust evidence about the effectiveness of the programme.

OUTPUT

Number of Incredible Years Autism courses delivered and attendance data

A total of 5 IY Autism parent groups were delivered between September 2015 and June 2017.

- The groups have been delivered across the county in Newtown, Brecon, Ystradgynlais and Llandrindod Wells.
- 40* Powys parents were registered as attending these groups.
- Number of children – 34.
- Of the total number of parents, 18% (7) parents lived in Flying Start postcodes.
- Parents attended on average 71% of the programme.

*Unfortunately complete sets of pre and post measures are only available for 62% these parents

OUTCOMES

Mental Health and Wellbeing

- Parental mental health has an impact on child development, school readiness and anti-social behaviour.
- The General Health Questionnaire (GHQ-30) was used as a measure of parental mental health for IY Autism groups as this measure is required for all groups under the current parenting contract
- Of the parents that completed the GHQ*, **there was a reduction in the scores on the GHQ and this reduction was significant using a paired samples t-test**, see figure 1.
- Additionally, there was a **reduction in the percentage of parents in the clinical range from 33% (7) to 4.8% (1)**.
- As can be seen in Figure 1, prior to the group, the average scores were within the clinical range and this decreased to outside the clinical range post group. **The overall reduction in scores on the GHQ**, gives some evidence that **attending the IY Autism course helps to improve parental health and wellbeing**. This is also supported by many of the qualitative statements shown below.

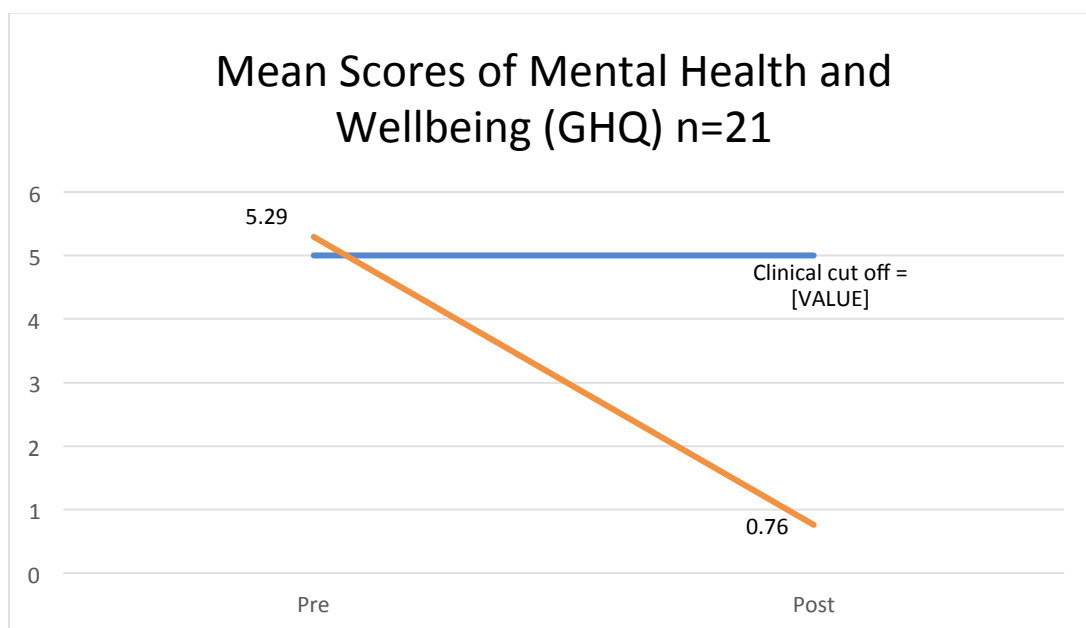


Figure 1. Pre and post-group mean scores of Mental Health and Wellbeing based on the GHQ. *21 full sets of data

Problem behaviour and frequency of problem behaviour

- The **Eyberg Child Behaviour Inventory (ECBI)** is a parental rating scale which assesses behaviour in children aged 2 – 16 years, using two scales: the ‘Intensity’ scale which measures how frequent behaviours occur-, and the ‘problem’ scale where the parent is asked to identify whether each item is a problem or not.
- Parents attending the IY Autism programmes completed the ECBI at the start of the course and again at the end of the course. This measure was used as it is required for all groups under the current parenting contract. A total number of 25 parents completed the ECBI.

Frequency of Problem Behaviour

- At the start of the course, 48% (12) of parents that completed measures at both time points reported at clinical levels in terms of the frequency of problem behaviour in their child. This reduced to 36% (9) at the end of the course.
- The average score on parental reports of the frequency of problem behaviour was in the clinical range pre group. This dropped to well within normal limits by the end of the group, see figure 2. **This result is significant using a paired samples t-test.**
- This shows that there is an **improvement in parental reports of the frequency of problematic behaviours for parents who attended IY Autism groups.**

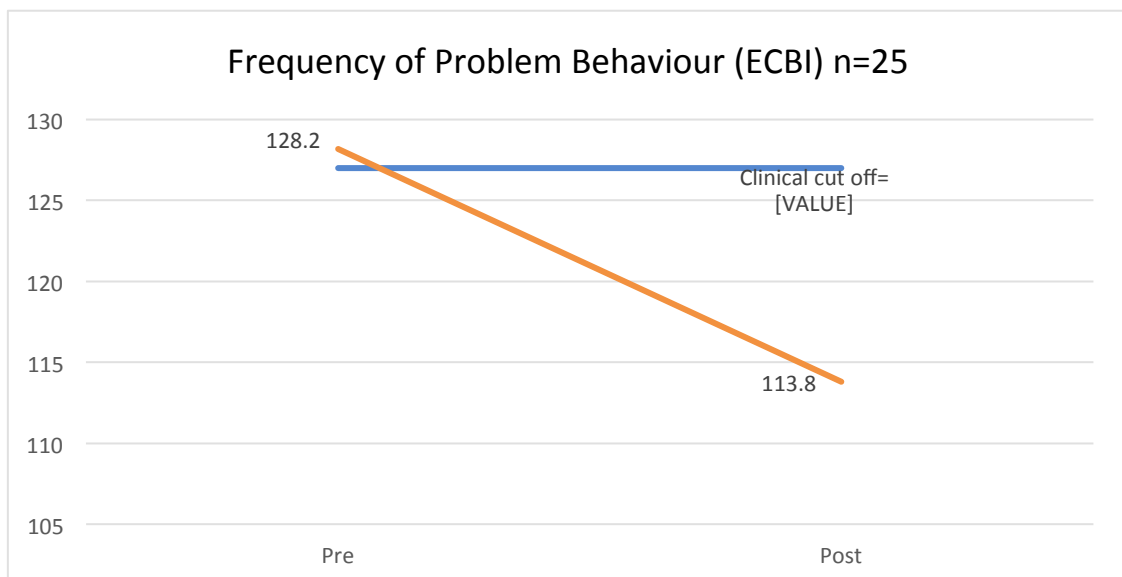


Figure 2. Mean scores of frequency of problem behaviour for parents who completed the ECBI pre and post group.

Number of Problem Behaviours

- At the start of the course, 60% (15) of parents that completed measures at both time points reported clinical levels of problem behaviour in their child. This reduced to 36% (9) at the end of the course.
- The average score on parental reports of the frequency of problem behaviour was in the clinical range pre group. This dropped to well within normal limits by the end of the group, see figure 2. **This result is significant using a paired samples t-test.**
- This shows that there is an **improvement in parental reports of the number of problematic behaviours** and provides evidence that attending an IY Autism course helps reduce the number of behaviours parents find problematic and also the frequency of problem behaviour, possibly indicating that they have learnt new strategies for managing problem behaviour and coaching more pro-social behaviour.

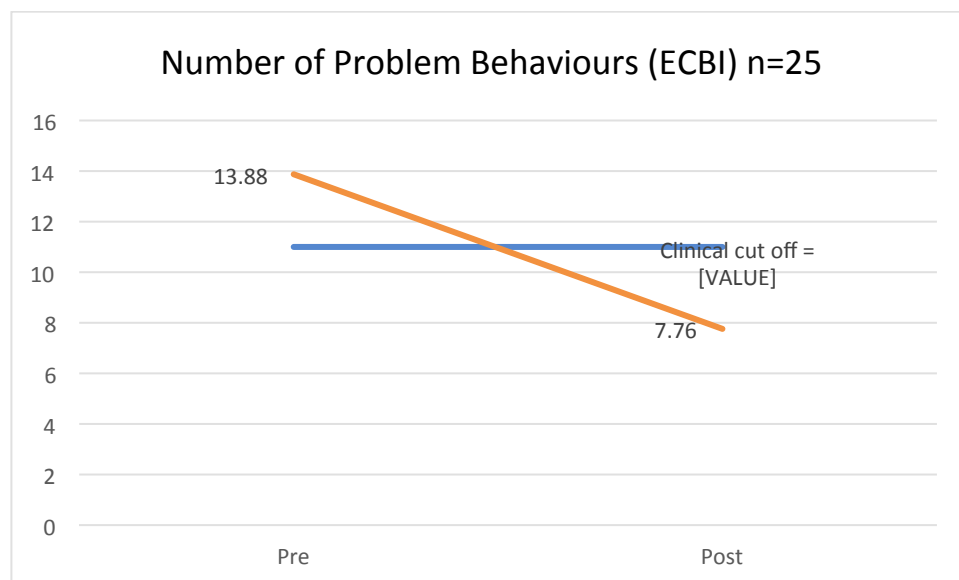


Figure 3. Mean scores of the number of problem behaviours based on parents scores on the ECBI pre and post group.

The above results provide new evidence for the effectiveness of the IY Autism programme. These positive results suggest that the programmes were delivered with

a high level of fidelity.

Parent Feedback

The Incredible Years® Autism Programme End of Course Satisfaction Questionnaire is given to parents to complete at the end of the last session. It asks 37 questions relating to: (1) the overall programme, (2) usefulness of teaching format, (3) usefulness of specific parenting techniques, (4) evaluation of the group leaders, and (5) the parent group. 33 of the questions are rated on a seven-point scale with a score of one being a negative response, four neutral/same, and seven a very positive response.

Parents were asked whether they would recommend the programme to other parents:

- **100% of parents said they would recommend the programme to other parents**
- 78% of parents said they would strongly recommend the programme
- 22% of parents said they would recommend the programme

Figure 4, below details the response from 18 parents who attended the IY Autism programme and completed the full final evaluation questionnaire.

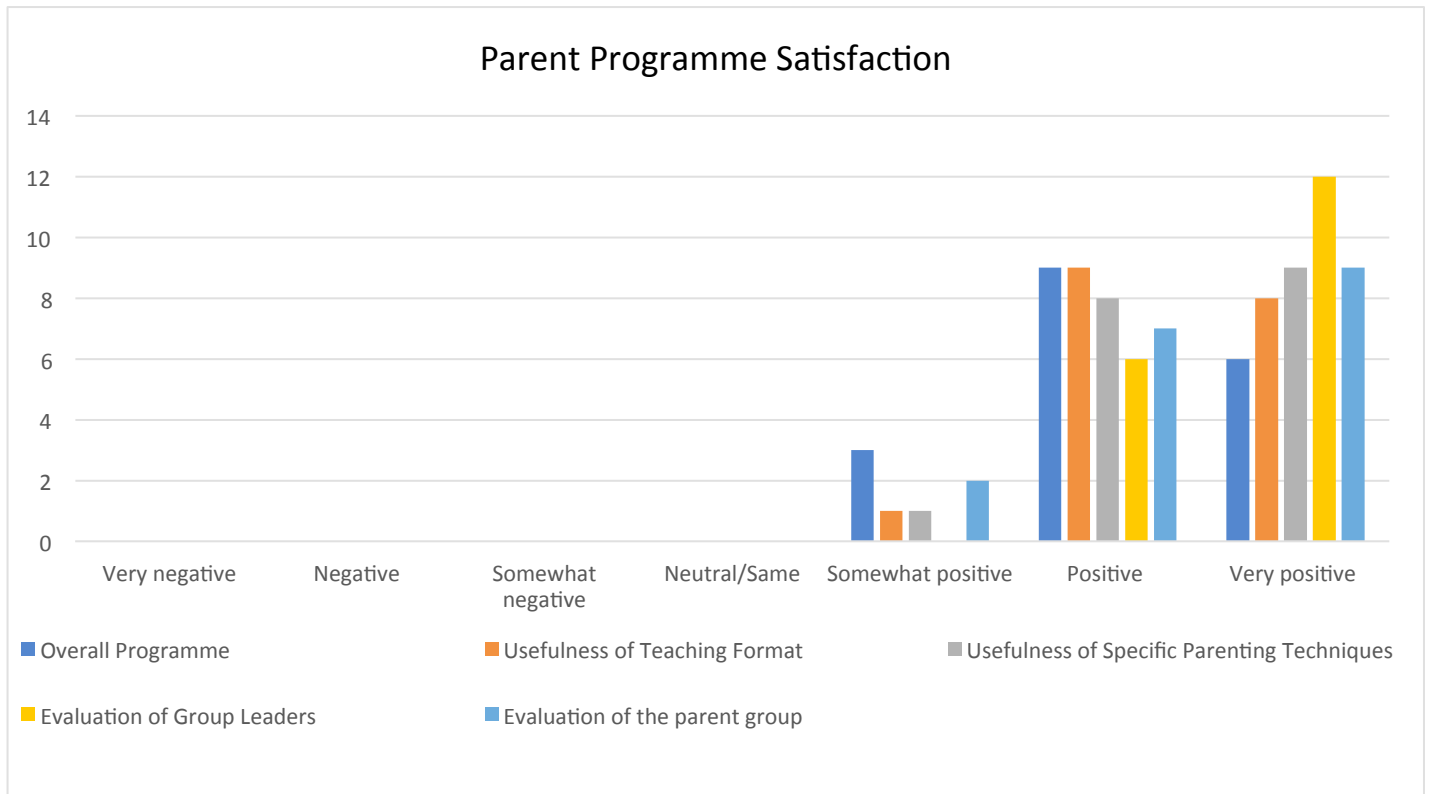


Figure 4. Scores on the parent satisfaction questionnaire completed post group.

As can be seen in Figure 4, all parents scored the programme positively in all aspects, with the majority of parents giving either positive or very positive feedback.

Parents were also asked questions on their opinions of the programme:

How could the programme have been improved to help you more?

- “I think the weekly sessions could’ve done with being 30 minutes longer as at times it did feel rushed but I understand with work commitments this extra 30 minutes could make it less appealing for parents to attend.”
- “Its perfect!”

At this time do you feel the need for additional parenting assistance?

- “No I am very happy I have been provided the foundation steps to carry on with.”
- “It would be nice to keep meeting.”

What did you see as the main benefit of the Autism Spectrum and Language Delays programme?

- “It empowered me to be able to be the best parent I can be and gave me the confidence to parent my autistic child in the best way possible.”
- “Without wanting to sound really corny, it has saved my sanity, probably saved my marriage and improved family life greatly. We no longer live in fear of meltdowns and view our son with much greater focus on his positives. From this – he has become calmer, his emotional and social skills are developing, his behaviour is improving and we feel more confident in our abilities to parent him. Thank you very much for providing this for us. It has been so valuable.”
- “I feel more confident on how to handle the certain situations. I feel optimistic about the future. I have learned a lot.”
- “Talking to other parents, finding out we are not alone”
- “It has improved my confidence and ability to parent my child. Help me to stay calm and know that others are experiencing the same as me.”

Case study

The following ‘case study’ was produced by two present who attendee an IY Autism group in South Powys.

Our IY Story

Rafferty has always been described as ‘quirky’ from a young age due to his conversational eloquence, bookish manner, obsessional behaviours on topics of interest and fiery temperament. Initially we found these qualities endearing but with the arrival of Rafferty’s younger brother and then Rafferty’s entry into the education system it became apparent that these quirks were becoming increasingly domineering, destructive and divisive in both family and school life.

Desperate and at the end of our tether, we contacted a private educational psychologist who suggested Rafferty presented with signs of having an Autism Spectrum Disorder. Following several months of assessment with the local SCAT team a formal diagnosis was made. The initial shock of the diagnosis soon turned to relief as we realised that we were not the terrible parents that we had felt so judged to be. However we were then were faced with the enormous and unknown challenge of parenting a child with ASD and having differing opinions and approaches as to how to do this. Jo took a much more avoidant approach whilst Scott would be more forceful in his manner. This led to inconsistent and unstable parenting and placed our relationship under a huge amount of strain. This inevitably had an impact on Rafferty

When speech and language therapist Caroline Jones, suggested that we join a parenting class 'Incredible Years' specifically for parents of children with ASD, we were sceptical. We were concerned that we were going to be unable to shake the label that we were somehow terrible parents but out of sheer desperation were willing to try anything.

We both decided to go as we believed it was important to work together on tackling Rafferty's challenging behaviour. With no word of a lie, The Incredible Years has saved both of our sanities, our marriage and family life. It has also reduced Rafferty's anxiety at home.

If all we had done was attend the first session and met other parents in the same or similar situation to us, it would've lifted a lot of the burden of loneliness, isolation and misunderstanding that we felt and the support from other parents throughout the 12 week programme cannot be underestimated. Celebrating seemingly small milestones which become giant leaps in your child and families development connects you in a unique and powerful way.

Prior to the course we had become fixated on the minutiae of every meltdown and failed to notice the successes. Within a week, our mind-set had changed and we could no longer remember what challenges we had faced over the week but could list on two hands positive achievements that Rafferty had made; be that he had put his own trousers on or told us he was scared and needed to leave a situation.

We both spent one to one time with Rafferty, getting to know him, to play with him, to enter his 'spotlight' on his terms and be led by him. This for us, has been fundamental and when things have become awry or we have had a wobble we revert back to this and can see instant changes in how he engages with us.

We have introduced strategies to promote emotional regulation for the whole family and now all practice using yoga, breathing and 'calm down thermometers'. When we use puppets, it helps Rafferty communicate in a way in which we can see beneath the layer of his Autism and this has been a truly emotional and bonding experience.

We are parenting from the same page for the first time, praising each other when we do things well and family life is now fun and enjoyable. We look forward to spending time as a family and no longer use work as a way to escape the chaos.

We started the course believing that we needed to know how to fix Rafferty's 'bad' behaviour and we have come away from it realising that his behaviour is the tip of the iceberg. If we can lay a solid foundation based on positive communication, play, praise, emotional and perseverance coaching then the behaviour manages itself.

We would absolute recommend this course as a 'must-do' for all parents of children with ASD. Having a child with Autism is challenging; having a support network and strong foundation from which to parent from has made us realise how lucky we are to be blessed with rearing such incredible children.

Feedback from leaders

Group leaders involved in running the IY Autism programme were asked for their feedback in order to contribute to this evaluation. Responses to a number of structured questions are shown:

How have the groups benefited parents you have worked with?

- Growth in confidence and skills in dealing with difficult situations and knowing how to respond to their child
- Reports of reduction in problematic behaviour
- Increase in interaction between child and parent, enabling increased communication.
- Increased tolerance in the child in enabling parent to play alongside and/or take part in activities
- Increased independence in the child and parents' ability to enable that to happen whereas before the group they may have done too much for the child

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What has been the response of parents?

- Highly positive
- Some comments that for those with children that are non verbal they would appreciate vignettes that have children at the same developmental stage to theirs
- Wish it had been around before
- Would have liked the sessions to be longer/ and possibly more than 12 weeks but with extra support when the group finishes
- High level of friendships made within the groups which have continued

What has your experience been as a group leader?

- Very humbling and the feeling of honour to be in a position to share in the successes and sometimes lows with the families
- Increased my confidence in dealing with group dynamics and in how I impart knowledge as well as facilitate this in others
- Enjoyed working with another colleague and gaining a different perspective.

How does running the group fit with your current role?

- Allows me to work more intensely and frequently with families that may be on my caseload

- Enables proactive intervention and for core skills to be learnt for the families which may reduce the incidence of crisis and high levels of problematic behaviour in the future.
- Able to trouble shoot issues within the group and refer this back to behavioural theory and principles of IY which is LD Nurse core business
- Encouraged use of further/child interaction which is SALT core business

How do you see the groups fitting in with strategic pathways for your service?

- All families where children are on the pathway for an assessment or newly diagnosed will be offered the chance to be able to attend the group
- Possibility of this being the first step to specialist services
- Possibility of need for programme to be delivered within the home on the rare occasion that the family is unable to access the group
- Early intervention

Are there any pitfalls or recommendations for changes to the way groups are run?

- Ensure that all families that attend have a strong suspicion of a diagnosis or have a diagnosis of Autism
- No more than 8 attendees per group
- Really helpful when both sets of parents attend we have had this happen in each group that has run
- Have some examples and prepare how you can differentiate the practices for non verbal children

Conclusion and Recommendations

The pilot evaluation of the IY Autism parent programme in Powys has shown excellent results in terms of: feedback from parents, outcomes from parental reports and feedback from group leaders.

Parents report high levels of satisfaction with the programme. There are statistically significant improvements in parental mental health and well being and statistically significant reductions in the frequency and number of problematic behaviours reported by parents. These improvements are much greater than would be expected by chance. There are also reductions in the percentage of parents reporting at clinical levels on all measures. Unfortunately pre and post outcome measures and satisfaction questionnaires were not available for all parents who attended IY Autism

groups, it will be important to ensure arrangements are in place to collect full sets of measures from future groups.

Powerful qualitative reports document the impact that the programme has had on parents who attended the groups.

The delivery of groups by committed and skilled Autism specialist who have had access to local training and supervision has contributed to the very positive outcomes. The decision to integrate the IY Autism groups into the general programme of IY parenting groups coordinated by commissioned providers has supported the effective roll out and delivery of the groups.

Given the above very positive evaluation the following is recommended:

1. The IY Autism parent programme is included in the new specification for parenting support with coordination by the commissioned agency and delivery by partner agencies who are Autism specialists.
2. IY Autism groups are offered as targeted provision for parents of children (2- 8 Years) with a diagnosis of Autism, or who are undergoing assessment by the Social Communication Assessment Team. Groups are offered routinely as part of a post assessment pathway.
3. In order to meet demand, a minimum of three groups are offered across the county each year.
4. Group leaders continue to receive regular video supervision from an accredited trainer with support to achieve accreditation.
5. One leader is identified who, having achieved accreditation, can train as a peer coach in this programme and work towards accreditation as a peer coach. This would enable the building of a 'peer coach' supportive infrastructure for this programme to ensure sustainability in the long term.
6. There are termly meetings between IY coordinators and Autism group leaders to facilitate joint planning of upcoming groups.
7. Complete sets of pre and post measures are collected from all parents in future groups and further data is collected to add to the data reported here and to ensure ongoing monitoring of outcomes.

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