



THE MINISTRY OF PARENTING

PROMOTING CREATIVITY IN PARENTING SUPPORT A COMMUNITY INTEREST COMPANY

Report on two pilot Incredible Years® Autism Spectrum and Language Delays programmes

A/S Project -February 217



Introduction

I have been delivering the Incredible Years® (IY) pre-school and school aged programme parenting groups for around 20 years and have seen the positive impact the programme has on families. The IY programmes are designed primarily to be used with parents of children who display varying degrees of social, emotional and behavioural problems and many of the families I worked with had children diagnosed with ADHD and or a conduct disorder.

Over the last few years I began to see an increase in parents with children on the Autism Spectrum been referred to my school aged groups. Even though I believed the IY core set of principles are relevant to all “parents” I was concerned that the programmes were not specific enough to the wide and varying issues parents with a child with autism have. I was excited to learn that Carolyn Webster Stratton author of the IY school aged programme had developed a new IY parenting programme, specifically targeting parents of children on the autism spectrum and/or with communication difficulties.

This programme is called the “Incredible Years Autism Spectrum and Language Delays programme” Webster-Stratton, C (2015). I was very fortunate to attend the training in this programme by the author herself in 2015 and in early 2016 project funding was secured to develop the programme in North Essex.

Where our project is based

The project was named the A/S group and was funded to support families in North East Essex (the Colchester Borough and Tendring district)



Our A/S group target population

An estimated 41,600 young people were living in the Colchester borough in 2012 (those aged 19 years or younger), which accounts for approximately 24% of the total population. The 2011 census showed 26,155 dependent children living in Tendring. Thus, a minimum

population of 67,755 children in the project area leads us to calculate that there is currently about 746 children and young people in the project area with Autism. Numbers of children with a statement of special educational needs, with autism as the main category of need (January 2013) in North Essex, was 253. 132 of these children are from Tendring which has one of the most deprived wards in the country

The population aged 18-64 predicted to have autistic spectrum disorder;

	2012	2020	2030
Colchester Borough	1,145	1,033	1,027
Tendring District	799	823	868
Total	1944	1856	1895

(Essex Adult Autism Strategy 2014)

To ensure the project would reach the families the project worked with local services:

Autism Anglia is an independent charity which provides care and support to children, adults and families affected by autism. They support around 1,337 families per year across Essex and Suffolk. Jo Keys, a Head of Autism Advice Service supported the delivery of both groups 1 and 2.

Marketfield School 11% of children with special educational needs in state-funded schools have a diagnosis of autism. Therefore, in this project we felt it was important to involve a local special needs school. Marketfield School is a day special school for children and young people between the ages of 5 and 16 who experience moderate learning difficulties. They also have enhanced provision for pupils with Autism. 225 children attend Marketfield School and 40% of the children are on free school meals. Sarah Smith, a therapeutic support team leader at Marketfields, attended group 1 as a volunteer and then co-delivered in group 2

Emotional Wellbeing and Mental Health Service (EWMHS) People with autism have been shown to be more prone to mental health problems although research differs on whether they are more vulnerable than people with a learning disability. Affective disorders such as depression and anxiety are the most common co-morbid secondary psychiatric disorders. Rates of depression and anxiety have also been found to be higher among close relatives of people with autism. So, we invited Lisa Parker, an experienced Mental Health Practitioner from EWMHS (*NELFT NHS Foundation Trust*) to join the programme as a volunteer

Gosbecks Primary School With awareness that 70% of children with autism are educated in mainstream schools and that SEN (Special Educational Needs) provision is oversubscribed and underfunded, we were delighted when Jo Nightingale, a SEN LA (Special Educational Needs Learning Assistant) , requested to attend the programme.

The Programme

The IY Autism Spectrum and Language Delays 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. 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 and children on the autism spectrum.

In the two pilot groups, the programme was delivered over 12 weeks. We had a half-hour meet and greet time before each session and we delivered the session content over two and a half hours.

For the first pilot group we increased the age group to 8 years as children in the UK are often diagnosed later than in the USA. In the second pilot group we had a father with a child aged 10 years.

The parents

Parents of children aged between 2 and 10 years who had been, or were in the process of being assessed for Autism and /or speech delay, were invited to take part. 22 parents enrolled for the two courses and 20 completed the programme.

Of the two parents that withdrew; one had a child that was being assessed at the start of the programme; a few weeks in her child was not diagnosed with Autism and so did not feel the course would be appropriate. The other parent had a child with ADHD and Autism and she felt the ADHD traits were more of a parental management problem so was transferred to the Incredible Year's school aged programme.

Demographics

Number of parents started the A/S programme	22
Number of professionals attended and completed the programme	3
Number of parents completed the A/S group (over 80% attendance)	20
Number of targeted children	26
Number of siblings	16
Age of youngest child	2
Age of oldest child	10
Mean-age child in years	5.5

Number of mothers	18
Number of fathers	2
Number of grandparents	1
Number of foster parents	1
Marital Status of parents	
Single	28.5 %
Married/ Cohabiting	71.5 %
Parent Education	
Left school at 16	64%
Left School at 18	14%
Professional Qualification without degree	28%
Left education at 21	21%
Ethnicity	
White/Northern European	92%
Target child - Child Health and Development	
Diagnosed with ASD	16
ASD & ADHD	5
ASD & language delay	4
Other- foetal alcohol syndrome	1
Number of targeted children attending special need school	8
Number of targeted children in main stream education but with additional support	14
Number of targeted children in main stream education but on part time hours	2
Number of targeted children in nursey	4
Number of parents on waiting list for next course – when funding confirmed	11

The course evaluation measures

As part of the programme, parents completed a brief session evaluation at the end of each session and a fuller evaluation and at the end of the course. The parent also completed a pre and post Autism Parenting Stress Index.

The Incredible Years® Autism Programme Weekly Evaluations (www.incredibleyears.com) has five items regarding the helpfulness of: (1) DVD’s vignettes, (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, not helpful, neutral, helpful, or very helpful. Participants completed the evaluations at the end of every group session. The weekly evaluation forms guided the group facilitators in their planning, reflections and delivery style. The weekly evaluations consistently showed the parents were finding the DVD vignettes, content, teaching delivery, group discussions and home activities helpful or very helpful.

There a couple of “neutrals” on the use of practice exercises and this was often commented by the parent saying role-plays were helpful but they felt uncomfortable doing the practice activities in front of adults.

The Incredible Years® Autism Programme End of Course Satisfaction Questionnaire (www.incredibleyears.com) is given to parents at the end of the last session. It asks 37 questions: (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 one a negative response, four neutral/same, and seven a very positive response.

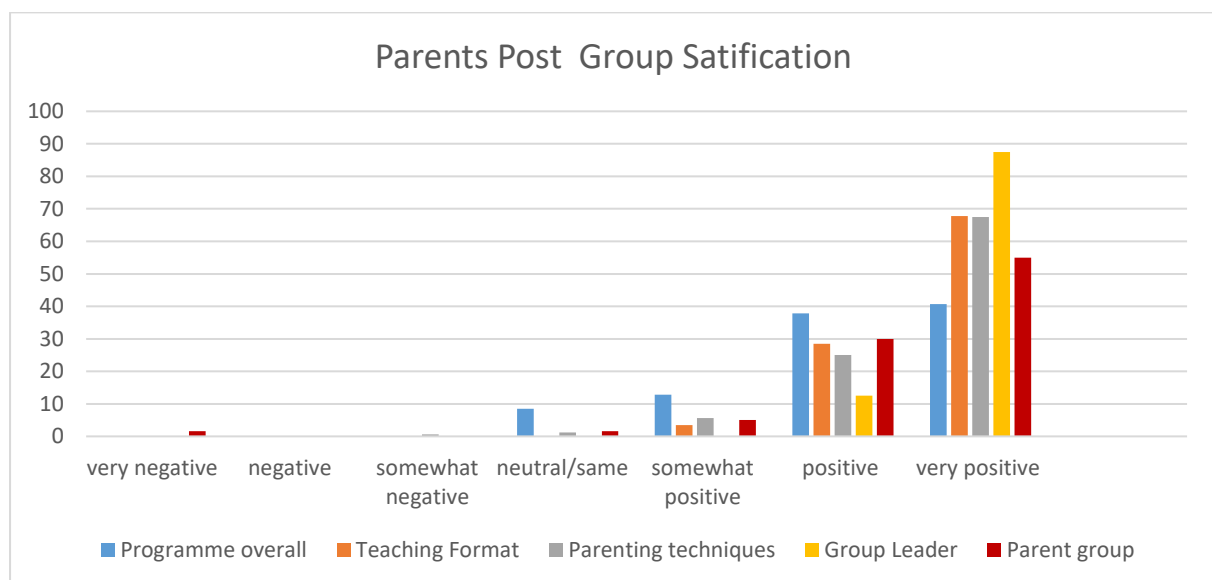


Table A

The 20 parents who completed the satisfaction questionnaire scored the programme highly (positive and highly positive).

In the programme overall the areas given a neutral/same/somewhat was in reference to the improvement in their child's self-regulation and imaginary play skills. 100% of the parents said they would recommend the programme to family or friends.

In the teaching format, the parent's discussion rated highest.

In the specific parenting techniques one parent struggled with emotional coaching. All the other parents apart from this parent rated the emotional coaching element as very positive (extremely useful).

All the parents rated the group facilitators as positive/very positive

In the parent group the 'very negative' score was in reference to meeting up with the group again and it was scored negative by one parent as they would not be able to meet the group due to her working hours (95% of the parents stated they would like to meet up again)

Parents were also asked:

How could the programme have been improved to help more?

- I feel it is a great course and can't think of any way it can be improved.
- I really can't think of any think that's been missed!
- I found the program really helpful.
- Perhaps a speaker with autism come in for a talk.
- I don't think I would change one thing. The content was so useful, the delivery brilliant, I have really enjoyed it.
- I had all the information that I needed to know about Autism and Language Delay.
- I could have done with the programme being longer to allow us time to cover course material, discuss our own children and dilemmas and to sometimes veer off course to discuss other issues which arise. To begin with I was concerned about relevance to my daughter as she is verbal, however it transpired that this was a building-block to the other content which was highly relevant.
- I don't think it could have been improved. It went at a good pace, was insightful, informative, and specifically targeted issues that children on the spectrum struggle with. As this is all new to me (diagnosis pending), it seemed just right.
- On line access to all the vignettes
- Peer-group meeting
- Eye opener especially in social coaching and praising
- A follow-on course or refresher to adapt the techniques to our children who may have changed and moved on developmentally
- It has been an excellent course with so much information sorry but I am not sure how it could be improved?

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

- The course covered a lot on the parenting side, fulfilled my needs. Any additional course would have to be on understanding autism as it is such a big spectrum I feel one course could not possibly cover everything.

- I think I would benefit from another course but on the autism spectrum in general, this course has covered all the learning side.
- Just some extra help on keeping my daughter's attention and concentration for longer periods of time.
- Not at present but perhaps in a couple of years' time.
- Help and guidance with educational concerns but I think this is for the ECC Education/SENCO at school.
- I do wish we had a few more sessions, mainly because the teaching strategies have been so helpful and it would have been nice to get some more strategies and build of these given through the sessions.
- Help with managing anxiety, help with social stories, help with supporting child academically as she progresses through school, any more courses on understanding ASD- it was invaluable to have Jo from Autism Anglia on the course too.
- Having completed the course, I think I just need to be mindful of actually implementing what we have learnt, and at this time I don't think I need further assistance. However, as my daughter grows and the challenges change it may be useful to have advice for older children
- I am content to keep applying and re-evaluating the strategies I have learnt in this programme
- Stress management for parents... I am trying to model "calm"
- Sensory assessment
- I would like to do this programme again in the future to be keep reminded
- Any additional support and advice is hugely appreciated.

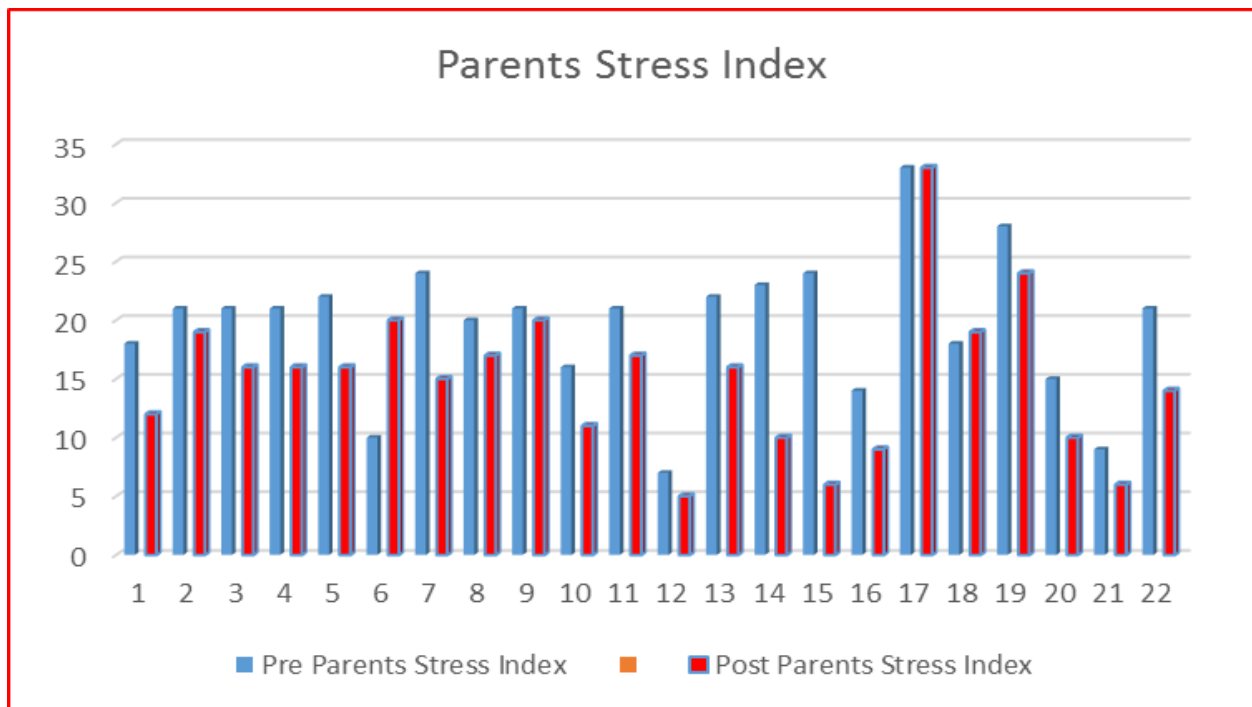
What did they see as the main benefit of the group programme?

- Understanding my child a lot more, how to relate, limit, coach and communicate so much better than without the course. It has improved our relationship greatly.
- Hearing from other parents and realising you're not alone! Also, how to improve my child's learning and social skills.
- Just a lot of help and advice with different ways of managing behaviours.
- Have insight into technique or how to help my child with emotional behaviour and praise.
- Inspiration for how to communicate with my often non-responsive child, effectively.
- It was very beneficial, in that by doing the 10 minute spotlight each day with my son and using the strategies, I have seen incredible changes in my son and with his vocabulary and language use.
- Language Delay, as my son is nearly 3 years old.
- It made me re-evaluate how I communicate with my daughter to aid her development- and to this extent it was life changing. This was done through course material, superb training and in sharing the other delegates battles, strategies and triumphs.
- Child-led/limit setting. How to be kind to yourself and meeting others

- An insight into typical behaviours of children on the spectrum and how to deal with it (compared to a neuro-typical child).
- It teaches me to change my negative comment to a positive comment to my child
- Given me the skills to interact with my child as he is very “in this own world” and it has been transforming
- Ideas and access to resources.
- Being able to talk and be heard
- Meeting as a group regularly to stimulate ideas
- A wonderful course, thank you so much for my added confidence.
- I feel my children have benefited from everything we have covered on this course. I think that over a longer period of time the benefits will be very noticeable and significant

Autism Parents Stress Index (APSI) is a measure of parenting stress-specific to core and co-morbid symptoms of autism, the APSI is unique. It is intended for use by clinicians to identify areas where parents need support with parenting skills, and to assess the effect of intervention on parenting stress

Table B shows the pre and post outcomes. **A decrease is a positive result.**



All but two of the parents who completed the programme had positive outcomes (reduced stress at home)

One parent scored 2 index sheets as both her children were on the Autism spectrum. This parent showed no change in child 1 and a slight increase in child 2. This parent was home teaching her children for part of the course and then the children were at school in part time hours.

One parent increased and they reported the increase to having a greater aware of the developmental milestones their child was not reaching and this parent is now going on to another course to learn Makaton (sign language).

Why parents wanted to attend the course

- Parenting skills
- More skills building for me
- How to engage my child
- I was recommended to attend
- Learn techniques to “enter” my child’s world
- Improve my child’s communication and social skills

What was the experience of coming to the group like?

- Lovely!
- Very positive atmosphere and amazing experience
- I was dreading coming to this group to start with but as we go along I learned a lot of helpful things and I enjoyed every session
- Fantastic
- Supportive
- Inspiring
- Useful

What did you get out of the group?

- Positivity
- Skills needed to educate and regulate and relate to my child
- I learnt a lot about social coaching
- Being a positive parent
- Life skills
- Support – you are not the only one going though it
- Strategies to cope better
- Help my child thrive

What changes have you seen in your child/family?

- Less stress
- More positivity
- Child led activities
- My son is social and we are practicing social manners
- I am trying a positive approach in my parenting
- Calmer and more confident parent
- My child has opened up to me

What message would you give other parents thinking about attending the group course?

- If you only ever do one course this is the one to attend
- For parents with special needs children this is essential and should not be optional
- This is very informative
- Everyone will benefit in attending
- Go as early as you can as the sooner you learn the strategies the bigger impact it can have as early intervention is key.

Parent testimonial for the course.

My 6 year old son was diagnosed with Autism, global developmental delay and significant speech and language delay aged 2 ½. I first heard about the 'incredible years autism spectrum and language delay program' when a letter came home from school.

The course really interested me as it was delivering a parenting program to help children with areas such as academic, social and emotional development.

Despite my interest I must admit I was a bit wary as there are a few programs out there, such as ABA based ones, which I'm not particularly keen on for my son. Plus, I was unsure whether my son would be ready for such a program - I couldn't have been more wrong!!

As my son is growing and developing and I'm learning more about autism I see how unique and wonderful he is. He interprets the world in a different, but not a wrong way to me and I have no intentions of changing him or trying to "normalise" him, but I do want to connect with him. This course does exactly that! It uses positive encouragement and helps strengthen language skills by using key words in the coaching so your child can learn what feeling they are experiencing.

When using the coaching I've seen nothing but big smiles from my son, which is so reassuring. There is no forcing just positive encouragement, he is still quite rightly able to express himself and say 'no' if he really doesn't want to do something, this is so important to me! It does however give me the knowledge of approaching situations differently than I might have originally done and so creating a much calmer positive outcome.

The course has also filled in a lot of blank spaces for me. For instance, I have always tried to ignore bad behaviour reward good, but sometimes I have been stuck as to how I continue once I've started ignoring him, also if he truly understands why I'm ignoring him! The course has taught me strategies I can use to help manage behaviour. It has also given me the tools to help my son self-regulate when he is feeling angry, which is important especially as he's getting bigger and stronger!

Parenting is hard, but throw the confusing constellation of behaviours that is Autism into the mix and it becomes even harder. For six years my little girl has been ill with serious digestive issues, but there's something else... For six years we have been passed from health service to service while the medical profession investigate what is "wrong". On suspecting ASD & hearing we will be added to another waiting list, out of desperation (and on the verge of

tears) I said to the Paediatrician: "What I really need are some strategies to navigate everyday life".

"Try Incredible Years AS Parenting Course it may help". Help, is an understatement. For just three hours on a Thursday morning I can relax, I am surrounded by people who will not judge me, but will share ideas, tips, listening ears, above all, they UNDERSTAND, we have grown as a group to have a lot of mutual respect, support each other & I have met people I think one day I will call my friends.

But at the heart of all of this is The Course. The information, strategies, the experienced but non-judgemental way it is delivered, the expertise of having representation from Autism Anglia, the role playing, the homework and the way we work through the strategies to fully understand them and practise them, has all been very powerful. This course has changed my perceptions of parenting in just 12 weeks. It is quite remarkable. I have also grown in my ability to understand the confusing world that is Autism.

There is no quick fix in dealing with a condition like Autism, but this course has equipped parents, like me, with tools to cope and understand.

Oh, and the next time I'm in the paediatrician's office and I hear a diagnosis that I have been dreading, yes there will probably be more tears. But now I know it will be ok, as I have some tools and strategies to deal with what lies ahead. And for that, I can't thank this course enough.

"I'm so glad I got a place on this course, our consultant recommended it to us and it's really helped all of us as a family already! Even the introduction was helpful, when you hear other parents discussing their children you realise you're not alone after all! Jeannie and the team are just fantastic, Jeannie is so warm and friendly I felt as home from the start and found she really thinks about your individual child to help you support them in the best way possible! My daughter has come on a lot, eve her nursery teacher has commended, she now gives us more eye contact and frequently uses the emotion and social coaching there we've been using with her to other people like her brother and friend. We have also found the pretend play and with puppets very useful, she loves to communicate with them and I've found she will calm down if one talks to her, overall I would really recommend this course to everyone!"

Messages post the groups

"I just thought I would let you know a member of staff came to me yesterday for some advice about her child, I explained the ABC and this morning she said it had worked! Her child kept getting up in the night wanting to be in her Mums bed, last night after using the ABC she stayed in her bed all night! And they had the time together this morning"

"Thanks for all the helpful information and support this year - I have really enjoyed the course so far and found it very useful. I have brought my son an egg spinning chair for Christmas. I feel like I am slowly morphing into one of the vignette parents!!!"

Feedback from the professional volunteers

- This course has been an amazing insight into Autism and I've taken lots of ideas back to the classroom
- The book is great
- The DVD clips were so informative
- The handouts are great to keep
- I feel much more confident in the class and have passed on my new knowledge to other staff members

References & web links

Autism Anglia www.autism-anglia.org.uk

Gosbecks Primary school www.gosbecks.co.uk

Market field school www.marketfieldschool.co.uk

NELFT NHS Foundation Trust www.nelft.nhs.uk

The Office for National Statistics www.ons.gov.uk Accessed on 13/1/2017

2014 Child Poverty Map of the UK

www.endchildpoverty.org.uk/images/ecp/Report_on_child_poverty_map_2014.pdf

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Webster-Stratton, C (2015) Manual for the Incredible Years Autism Spectrum and Language Delays programme for parents with preschool children, Seattle, US: Incredible Years Inc.

Recommended reading

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