

Parent training programme for autism spectrum disorders: an evaluation

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Abstract

Parents of young children often seek the support of professionals when experiencing difficulties in managing their child's behaviour. Parents of children with complex neurodevelopmental disorders, including autism spectrum disorder (ASD), are no exception. This paper describes a pilot Incredible Years parenting programme that was offered to a group of parents of children with ASD. A service evaluation suggested positive changes within a 12-week period, particularly in parental mental health, but also in child behaviour.

Key words

Parenting, behaviour management, autism spectrum disorder, Asperger syndrome, cross-agency approach, parental mental health

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Introduction

Following the Wanless Report,¹ a new service was set up across the county of Conwy in North Wales to promote the psychological wellbeing of children and young people. This followed the Wanless principles of managing demand and remodelling services in order to provide an accessible and equitable non-stigmatising service for children and families, and the post of specialist behaviour practitioner was created. The aim was to support the parents of children aged five to 11 years who had mild to moderate behavioural difficulties, and also the staff working with these families.

The Incredible Years parenting programme² was well established in the area and had been running for approximately five years. Within four years of the new post's introduction, it became increasingly evident that referrals were for families with complex difficulties, such as autism spectrum disorder (ASD). It was decided to pilot a group, co-facilitated by the behavioural practitioner and clinical psychologist from the specialist child and adolescent mental health service (CAMHS), for parents of children who either had a diagnosis or were currently under assessment for ASD.

This paper describes a local pilot Incredible Years Basic programme² that was offered to eight parents experiencing difficulties in managing children with ASD, and the results of a service evaluation. It includes a literature review of interventions to support parents and children with ASD, and how the programme aimed to meet the needs of parents while still maintaining programme fidelity.

Autism spectrum disorder

There are a number of definitions of autism, but the one adopted by the Welsh Assembly Government following the World Health Organization is a useful one. It includes ASD among a group of pervasive developmental disorders, which are 'characterised by qualitative abnormalities in reciprocal social interactions and in

patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities'.³

Often seen as 'mild autism', Asperger syndrome sits under the ASD umbrella. Asperger syndrome was first defined by Hans Asperger, a paediatrician who identified a consistent pattern of abilities and behaviour that predominantly occurred in boys. This included lack of empathy, little ability to form friendships, one-sided conversations, intense absorption in a special interest and clumsy movements.⁴

Prevalence of ASD, if broadly defined, is 60 in 10 000 of under-eights in Wales, as in Scotland,⁵ with 66% to 75% of these appearing to be high functioning. The autism spectrum includes people with severe learning disabilities and little or no verbal communication, through to those who have an average or high IQ, including people who have Asperger syndrome. All who have ASD share three types of impairment, which include difficulties in:

- Understanding and using communication (verbal and non-verbal)
- Understanding social behaviour, affecting their ability to interact – they tend to be literal thinkers and interpreters of language, so may fail to understand its social context
- Thinking and behaving flexibly, which may be shown in restricted or repetitive activities.⁵

A considerable proportion of children with autism exhibit behaviours such as hyperactivity, inattention, obsessive-compulsive symptoms, sleep disturbances, aggression, and self-injury.⁶ Challenging behaviour is therefore common in children with ASD. Studies also suggest that 75% of children will have some learning difficulty, which is also a risk factor for behavioural problems, and 41% of children with mild to moderate or severe learning difficulties have severe emotional behavioural disturbance.⁷ Attention deficit hyperactivity disorder (ADHD) is the most common psychiatric disorder co-morbid with ASD, and so children are likely to benefit from interventions to manage the ADHD symptoms.⁸

◀ Working with children with ASD

Children with complex neuro-developmental problems, including ASD, present a challenge to both their families and the clinicians who work with them. Many present with co-morbidities, including ADHD, conduct disorder, significant anxiety problems, obsessive compulsive disorder, depression, tics, Tourette syndrome, bipolar disorder, specific learning difficulties, severe learning disability, epilepsy and developmental co-ordination disorder (dyspraxia). These often complex presentations require multidisciplinary and multi-agency management.⁵

Recent policy documents such as the National Service Framework (NSF) for children, young people and maternity services⁹ articulate the need for specialist services for children with ASD to be provided in a seamless fashion, as close to the child's locality as possible (Standard 9). This stresses the importance of effective multidisciplinary and inter-agency working in order to meet the child's needs effectively and without undue delay. It also emphasises that 'universal services' have a clear role to play in child mental health, though ready access to appropriately skilled specialist mental health professionals is also needed for those children who go on to require it.

The *ASD strategic action plan for Wales*⁵ provides a framework for the development of services for this client group. Many other documents and initiatives have informed and directed the work carried out to meet the needs of children with ASD, such as *Making life better for people with autism and Asperger syndrome*¹⁰ and *Children and young people: rights to action*.¹¹

*Everybody's business*¹² emphasises the importance of multidisciplinary and multi-agency working and provided a framework for the delivery of child mental health services across four tiers. Originally described in 1995,¹³ the tiers describe the levels of intervention that families may encounter, with Tier 1 being the most frequently accessed (including health visitors, school nurses, GPs, social workers and teachers), Tier 2 being specialist posts, Tier 3 consisting of the traditional CAMHS team (psychologists, nurse therapists, social workers, psychiatrists and others) and Tier 4 the in-patient specialist services. With this in mind, the current intervention provided an opportunity for the sharing of skills across Tiers 2 and 3. More importantly, families were provided with an evidence-

based intervention to address the conduct problems that their children presented with. This was delivered by clinicians who had expert knowledge in the delivery of parent training interventions, as well as specialist knowledge of children presenting with social communication difficulties, in particular children with ASD.

Interventions for ASD

There appears to be little evidence about treatments to support children with ASD, in particular medication or dietary changes. In terms of challenging behaviour, which is extremely common in these children, the Welsh Assembly Government cannot endorse or recommend any particular intervention.⁵ It recommends multi-agency delivery as previously discussed.

Solomon et al¹⁴ found some success in helping parents of children with ASD through a 20-week parenting group, concentrating on teaching facial expressions, emotions and problem-solving skills for boys aged eight to 12 years. In terms of behavioural difficulties, problems have often crystallised by the age of eight and become much more difficult to change.¹⁵

Behavioural approaches include a programme called the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), which in particular uses parent training to help them understand the way children with ASD think, learn and generally experience the world.⁶ It uses natural reinforcements, promotes structure and predictability and uses consequences to behaviour. It also promotes visual cues and symbols, uses rewards to shape behaviour, both tangible and social, and time out for discipline strategies. Outcomes also showed that parents felt empowered, and behaviours generalised into daily life and routines, as well as improving self-help, social skills and communication, while reducing inappropriate behaviours and lowering parental stress.

Untreated conduct problems: outcomes

Studies have shown that untreated conduct problems lead to significant adverse psychosocial outcomes,¹⁶ including increased crime, substance use, mental health problems, increased teenage pregnancy rates, domestic violence, poor educational outcomes and lower paid employment. There is also a financial burden on society. From the ages of 10 to

28, average costs (including for care services, education, benefits, health and the justice system) may be £70 019 for untreated conduct disorders¹⁷ – 10 times higher than those with no problems.

Various figures have been published for costs of interventions. The National Institute for Health and Clinical Excellence (NICE)¹⁸ provides some comparisons between group and individual support. It suggests that it costs £500 or £700 per family for a group (clinic or community respectively) that meet for two hours per week over 10 weeks. Individual support per family costs £2000 if clinic based or £3000 home based, delivered over eight weeks for two hours per week. It would appear cost effective to offer group as opposed to individual interventions.

Incredible Years

Incredible Years is a well established programme in the local area, and there is a fair amount of research to support its efficacy. In a review of over 600 programmes, it was one of 11 identified as effective in treating children with early behaviour difficulties.¹⁹ Gardner et al²⁰ suggest that conduct problems can be successfully addressed through cognitive-behavioural parenting interventions, such as Incredible Years.

The NSF,⁹ *Parenting action plan*²¹ and NICE¹⁸ all recommend Incredible Years programmes as a favoured approach. It is certainly recommended as an intervention for behavioural difficulties, and given the components of the TEACCH programme and its efficacy as an intervention, it was reasonable to consider that the Incredible Years programme could be an effective intervention for the management of children with ASD.

Course structure: the eight key skills

Incredible Years covers eight key skills in behaviour management, as well as helping children to problem solve and parents to manage stress and anger. While maintaining programme fidelity, the sessions were geared at supporting parents of children with ASD, in that parents understood why the particular strategy would support their child.

Francis⁶ suggests that behavioural techniques should form the predominant approach in supporting parents of children with ASD. She refers to interventions where Skinnerian-based techniques such as immediate reinforcement form the major

part of the intervention. She acknowledges that, although new techniques have evolved in the support for ASD, behaviour analysis still remain at the core.

Service evaluation

The service evaluation aimed to explore which psychological measures were useful and what changes had occurred as a result of attending the 12-week Incredible Years parenting programme that was provided for parents of children with ASD.

Methods

Participants

All referrals into the programme had either been or were in the process of being assessed by the local CAMHS team. All target children presented with significant conduct problems, social communication difficulties and/or complex neurodevelopmental problems, and were under assessment to rule out ASD or had received an ASD diagnosis already. Over half had also been referred to the behaviour support team due to behavioural difficulties, and a lot of work had been done in terms of building relationships. This has been shown to improve the engagement with families.²²

Eight parents agreed to attend the sessions offered, and all seven target children were boys (mean age was eight years). At the start of the intervention and following a period of assessment by the CAMHS team, three of the target children had received a diagnosis of ASD with co-morbid anxiety, one a diagnosis of ASD and ADHD, two presented with significant anxiety symptoms and social communication difficulties (a diagnosis had not yet been reached) and one had a diagnosis of ADHD. All the children presented with significant conduct problems. The age of the children may be a reflection on the degree of ASD, as those high functioning children tend to be diagnosed around this age.⁵

As a service evaluation, research ethics approval was not required,²³ though the project was reviewed by the local NHS governance department.

Measures

For the purpose of data collection, four formal measures were used, and were administered at an introductory session and at the end of the programme. In addition, a qualitative feedback questionnaire was designed and administered to the parents at the end of the programme.

Key points

- A 12-week Incredible Years Basic parenting programme is a useful intervention for parents of children with social, emotional and communication difficulties
- Parents of children with autism spectrum disorder are at increased risk of mental health problems
- Multi-agency working is more cost-effective and enables professionals to learn from each other

Parental mental health

For the purpose of measuring parental mental wellbeing, the General Health Questionnaire (GHQ-30) was used.²⁴ This is a self-administered screening tool and the clinical cut-off score on this measure is five. This measure has been shown to be reliable as a measure of general wellbeing.

Child behaviour problems

As a means of gaining a measure of the frequency of problem behaviours and the degree of the problem that the parent considered the behaviour to present them with, the Eyberg Child Behaviour Inventory (ECBI) was used.²⁵ The clinical cut-off score is 127 for the intensity of behaviours and 11 for the degree of problem that these behaviours present the parent with.

Child's social anxiety

It is well recognised that children who present with complex social communication difficulties also present with significant social anxiety problems. The Social Worries Questionnaire²⁶ was used to assess the degree of social worries that the parent considered their child to have.

Child's social communication profile

The Australian Scale²⁷ was used as a measure of the child's social communication difficulties as seen by the parent.

Qualitative feedback

Each parent set at least one goal at the beginning of the course, which was reviewed at the end. Weekly evaluations also provided an indication of whether the co-facilitators were meeting parents' needs, and also to collect qualitative feedback.

For the purpose of gaining feedback from parents about the intervention, a qualitative questionnaire was designed to elicit parents' view about the content of the programme, the venue, timing and whether they would recommend others attend a similar programme in the future.

Delivery of the programme

The course was delivered by two trained co-facilitators, supported by a student social worker. The venue was a community building in the local area, and appeared to suit the group's needs really well. It provided a relaxed atmosphere, away from the clinic, with good parking facilities and it was central for the families who attended. This may have contributed to the good up-take for the group.

The programme ran for 12 weeks, with two hours of sessions per week, and consisted of the criteria recommended by the NICE guidelines on the treatment of conduct disorders.¹⁸

Each session was delivered according to the manual to ensure programme fidelity, with attention paid to how it related to children with ASD. Examples include:

- In sessions on play, coaching behaviours, through the use of descriptive commenting was emphasised. Children with ASD may avoid social play and lack social and emotional reciprocity, and coaching can help address these skills to some degree. These children do not learn through modelling in quite the same way as most children
- In setting limits, prompt cards were useful to fit in to the visual world of children with ASD, along with other visual cues to reduce anxiety and help with a transition. Setting limits is important for children with ASD as they can become quite obsessive about a particular interest
- As children with ASD can prefer their own company, this was useful when discussing time out and whether it was appropriate for their particular child
- Children with ASD can be poor problem solvers, and the programme looks at how parents can help children to develop problem-solving skills
- Consequences imposed by parents were kept to a minimum as children with ASD can be poor at learning from consequences of their actions.

Results

General Health Questionnaire

The mean GHQ-30 score for the participants reduced from 4.25 pre-group to 1.87 post-group. This had the most significant change out of all the measures used, in particular for Parent 1 and Parent 7 (whose scores reduced from 15 to nought and 11 to one respectively). One (Parent 8) had increased scores (from nought to 10), but this was explained by stressful work events.

Eyberg Child Behaviour Inventory

The mean ECBI intensity of behaviours score reduced from 156.5 pre-group to 145.5 post-group. This remained above the clinical cut-off of 127, though a dramatic reduction was not expected given the nature of the children's conditions.

The mean ECBI degree of problem score reduced from 12.75 pre-group to 9.13 post-group. This suggests that parents were managing their children's behaviour more effectively as it no longer posed the same problem to them. It is interesting to note that Parent 8, after scoring high on the GHQ, still demonstrated a positive change to their child's behaviour (scoring 11 pre-group and four post-group).

Other scales

Changes in scores for the Social Worries Questionnaire and Australian Scale were not significant.

Participant feedback

Feedback from group participants was positive, with strong emphasis on sharing ideas and feeling less isolated. A comforting reassurance was gained by the common theme of ASD:

I did the Incredible Years course a few years ago and whilst it was incredibly useful and a fantastic course... I felt quite frustrated that it didn't always apply to [my child]... Doing the course a second time was more beneficial because of the different slant. Being with other parents going through the same sort of struggles was one of the most beneficial aspects of the course... Parenting is such an important skill, and if you haven't had particularly great role models it is vital to have something like the Incredible Years to show you a more informed way (Parent 7). I have really enjoyed coming to this course. I now feel I am not the only parent with a child doing all these strange things... I hope the group carries on to help other parents like myself (Parent 4).

Discussion

The average GHQ scores were significantly reduced. The parent whose score had increased, reported stressful work events at the time of completing the questionnaire, and had only attended half of the course, therefore, may not have received the full benefit. These scores had the most significant changes, which inspires hope, given that research has shown that parents of children with ASD have higher stress levels than parents of other disabled children.²⁸

The ECBI mean scores also reduced. Sometimes, increases can occur as parents start to 'analyse' their children's behaviour much more effectively. For the parents in this project, the ECBI degree of problem mean scores reduced as well, suggesting that their children's behaviour was not presenting the same problem to them as before.

The Social Worries Questionnaire and Australian Scale had minimal changes, and so will not be used for subsequent groups.

This was a pilot, and both co-facilitators felt that it was a successful start and good cross-agency working, where both facilitators learned from each other. Group feedback was extremely positive and supportive. Leaving enough time to plan the sessions, adapt them to this clientele and to try to individualise the treatment within a group context was seen as vital.

Conclusion and recommendations

This service evaluation has aimed to inform workers of the usefulness of a cognitive behavioural model in supporting parents of children with ASD, in managing their behaviour. The programme appears to have been particularly useful in improving parental mental health. It provided a place where parents could develop their skills in order to reduce the frequency of some of their children's inappropriate behaviours, and also reduce the impact of these behaviours on them as parents.

Working cross-agency was enriching for both facilitators, with their differing backgrounds and knowledge bases, and having the support of a third worker was extremely helpful. It was an enjoyable experience that can hopefully be built upon. This would provide an excellent opportunity to continue to run these specialised groups, and to research them more rigorously. Due to demands on the service and waiting list pressures within the Tier 3 CAMHS, no specialist parenting group is running at present.

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