

Supporting families with children on the autism spectrum to use structured teaching approaches in the home and community

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Editorial comment

In this paper, the authors describe the work of a Team whose main focus is to work with families on areas which are presenting difficulties for the child and the family in the home setting. The rationale for their work is given and the criteria for involvement is discussed and defended. Two case studies illustrate the type of work done and comments from parents show just how effective the service is. The team is small and waiting lists are long and all involved with families and children on the autism spectrum need to consider how to expand such work as it is clear how beneficial it is. If the family is well supported and is healthy physically and emotionally, then this will have positive spin-offs for the children and for those who live and work with them.

Introduction

The impact on the family of having a child on the autism spectrum is well researched. There is overwhelming evidence this can significantly affect the family and its functioning (Koegel, Schriebmann, Loos, Dirlich-Wilhelm, Dunlap, Robbins and Plien, 1992; Randall and Parker, 1999; Sharpley, Bitsika and Efremidis, 1997) causing greater parental anxiety and stress than other disabilities (Gray, 1994; White and Hastings, 2004).

These families may be faced with a wide range of challenges, affecting both the child's development and family functioning. Children's difficulties in eating, toileting and inappropriate social behaviour are major problem areas (Abbeduto, Malick Seltzer, Shattuck, Wyngaarden Krauss, Orsmond and Murphy, 2004; Bromley, Hare, Davidson and Emerson, 2004), as are sleep problems, including not falling asleep in their own bed, multiple night time awakenings and early waking (Polimeni, Richdale and Francis, 2005; Williams, Sears and Allard, 2004). Fixed routines and behavioural problems may severely restrict families' abilities to undertake routine community activities of daily life, such as shopping, eating out, or medical appointments (Gray, 1993; Koegel et al., 1992; Vaughn, Wilson and Dunlap, 2002). Research into siblings of children on the autism spectrum indicates that the majority are functioning well, and are no more vulnerable to adjustment problems than the general population (Pilowsky, Yirmiya, Doppelt, Gross-Tsur and Shalev, 2004; Kaminsky and Dewey, 2002). Nonetheless the experience of siblings can be challenging at times and affect their performance and mood (Fitzgerald, Matthews, Birkberk and O'Connor, 1997; Ross and Cuskelly, 2006).

A child with a disability can challenge parents' preconceptions of family life and parenting: their experience may differ greatly from their pre-birth expectations (Seligman and Darling, 1997). Such challenges may be heightened in the case of autism, where the parents' natural parenting styles or skills, and approaches suggested for typically developing children, may prove ineffective (Siegel, 1996; Waltz, 1999) thus reducing their sense of parental competence (Dunn, Burbine, Bowers and Tantleff-Dunn, 2001).

The stress under which these families find themselves is subject to a range of variables. These include the family's financial situation, adjustment to the presence of autism in the family, and the availability both of informal and formal support (Bristol and Schopler, 1983; Gray, 1994; Marcus, 1984). Statutory support can be vital, and research has shown the importance of effective educational (Whitaker, 2007) and social care input (Preece, 2000; Tarleton and Macaulay, 2003).

Service development in Northamptonshire

Since the late 1980s, a range of autism-specific provision has been developed within the county across the local authority and within the voluntary sector (Howley, Preece and Arnold, 2001; Preece, 2003), underpinned by the principles of the TEACCH programme (Mesibov, Shea and Schopler, 2005). The provision of advice and direct support to families was identified as a necessary aspect of the county's range of services, alongside developments in educational and care settings; and in 1994 the ASD Family Advisory Team (then called the Autism Family Support Service) began working with families.

ASD Family Advisory Team

The team's remit is to introduce the structure and consistency provided by structured teaching into the child's home and community, empowering parents to support their children at home. Interventions have two discrete but related purposes. These are:

- to develop visual strategies and tools to address the presenting problem(s) through helping things make more sense for the child
- to teach family members the skills required to effectively use these strategies and tools and understand the child's autism, so they can problem-solve within the TEACCH structured teaching model.

Interventions are grounded in the consistent use of the structured teaching strategies of the TEACCH approach (Mesibov et al, 2005). Key tools are:

- physical structure: clarifying the purpose of physical space, reducing distractions
- schedules: presenting information about what will happen and when visually
- work systems: providing organisational strategies to complete activities
- visual structure: helping with organisation, increasing clarity and providing instruction.

The team also uses related approaches that complement the TEACCH approach, such as Social Stories™ (Gray and Garard, 1993).

Methods of work

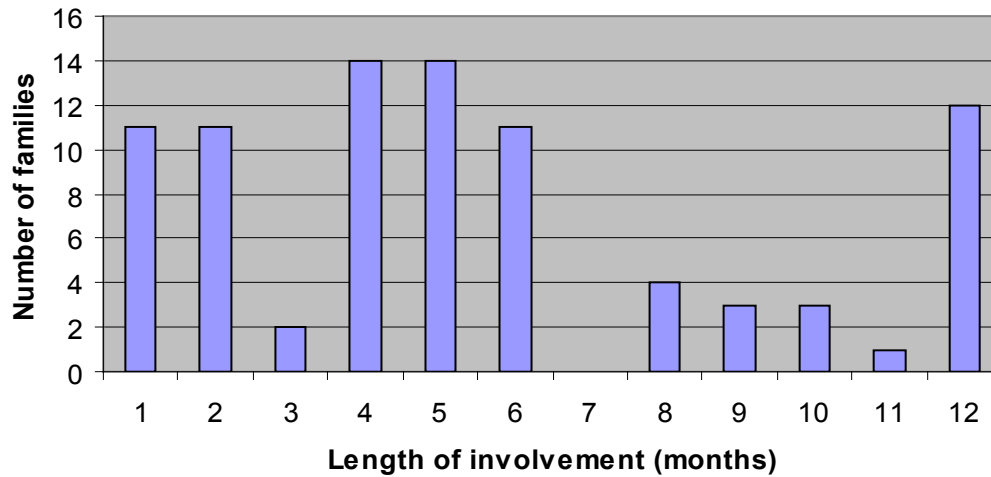
From the team's inception, it was acknowledged that service delivery must be differentiated, dependent on the presenting difficulties of the child, the family's existing skills, the need for direct modelling of skills, and their willingness to have professionals working in their home. Over time, a range of methods has been developed by the team. These range from providing the family with encouragement, through developing materials for them to use independently ('make and take') through to the working directly with the child and family in the home or community – wherever the behavioural issue is presenting. In this latter model of intervention, the worker first assesses the situation and designs and models the intervention, then teaches the parents to work with their child, finally 'stepping back', while continuing to support and advise the family.

In all cases, team members will meet with the primary care giver at home within a month from referral (this is usually the child's mother, although fathers/partners and siblings may be involved in implementing the strategies with the child). They explain the team's working methods, and identify with the family whether an intervention will be appropriate.

The worker assesses the child across settings – home, school, at short breaks or in the community – and liaises with family members and involved professionals, to identify the child's cognitive level, sensory profile, skills, interests and difficulties. This is vital as there are no 'off the shelf' solutions. Even when children present with the same problem the underlying causes may be very different, and each intervention is individualised to address the child's unique needs within their unique family context.

In 2007, the team supported 86 children and their families. The average length of intervention was five months. Some pieces of work (such as 'make and take') were shorter; while direct interventions could take longer, with some families requiring support throughout the whole year and beyond (see Table 1 below). At the time of writing (March 2008) the team is working with 34 families, with 22 further families identified as requiring a service. Lead time for a service depends on the type of intervention required and its priority, and the referral list is reviewed and prioritised with referring social work managers on a monthly basis. It can sometimes take 12 months before a worker is available to carry out direct work in the home. This is clearly far from ideal, and an increase in the size of the team is being sought to improve the situation. To ensure that these families remain engaged, and feel supported in understanding and working with their children, the team holds information evenings for families awaiting a service. These evenings include small group workshops on topics chosen in advance by the attendees (these have included getting out and about, food, bedtime, toileting and personal care), a parent panel (made up of parents who have used or are currently using the service) and opportunities for short individual consultation sessions.

Families using Northamptonshire ASD Family Advisory Team, 2007



Team structure

The team comprises one full time Senior Family Advisory Worker, and four part time Family Advisory Workers, working between 14 and 25- hours per week (a total of 2.9 full time equivalent staff). Overall management of the service is provided by the county's Team Manager for Social Care Services for Children with Autism.

All team members attend a three-day TEACCH seminar, providing underpinning knowledge and a broad understanding of the approach, and a five-day intensive TEACCH workshop, providing the opportunity to work with children across a range of ages and abilities, to assess within the TEACCH model, and practise the strategies and tools (i.e. physical structure, schedules, work systems, and visual organisation) which they will use in their work. Workers also undertake two-day training in Social Stories™ (Gray, 1994); and further training opportunities are provided. Of the current team, two have a University Certificate in Autism from the University of Birmingham, and two have undertaken training in the Picture Exchange Communication System (Frost and Bondy, 2002).

In addition to training, personal attributes and skills are crucial. Working in this model requires not only the range of characteristics identified by Peeters and Gillberg (1999) – to be *'bitten by the bug of autism'* and to have imaginative skills, the ability to adapt their natural style of communication and social interaction, willingness to work as part of a team, adaptability and humility – but also confidence, diplomacy, empathy, listening and negotiating skills as described by Dale (1996) to facilitate working with families in their own homes.

Partnership working: the planning contract

In all interventions, a planning contract is agreed and signed by the worker and family, identifying:

- the focus of the intervention
- what the Family Advisory Worker will do
- what the family members will do.

This contract forms the basis for the intervention, and there is a clear expectation that both parties will fulfil their obligations to complete the work.

Referral route

The ASD Family Advisory Team is part of the range of social care supports for children with disabilities provided by Northamptonshire Children and Young People's Service. As such, families must meet the service for disabled children's eligibility criteria, and referrals must be made via a social worker. Anecdotal reports from teachers, parents and local autism organisations, and the experience of team members, support research findings that negative attitudes exist towards, and stigma is associated with, receiving support from social services (Colton, Drakeford, Roberts, Scholte, Casas and Williams, 1997; Davidson and King, 2005). Some families are uncomfortable with the thought of having a social worker, and of seeking help and receiving support from 'social services', and decided not to use the service because of this.

Case studies

The following two case studies are illustrative of the work the team carries out. The children's names have been changed to protect their identities

Sally

Sally was 11 years old and lived at home with her mother, father, older brother and younger sister. She was taught within a specialist setting for children on the autism spectrum within a mainstream primary school. Sally was terrified of dogs and the situation had reached a level where she refused to go out with the family in case she saw a dog. This behaviour was limiting the family's ability to do anything together: one parent would have to stay at home with Sally while the others went out.

Following the referral, the allocated Family Advisory Worker observed Sally in school, at home and out for a walk in the community. At school she used a whole day schedule (printed words on removable cards) which she checked and manipulated independently. School staff identified that her fear of dogs was affecting her ability to join in with school activities taking place in the community and that they had recently stopped attempting to include her in community-based activities as her extreme reaction to dogs put both her and other pupils in danger. At home Sally was generally very independent and did not need or want 'help' from her parents. Although she had good verbal skills she was unable to say why she was afraid of dogs.

The worker accompanied Sally and her mother on a walk in the park to see how she reacted to coming into contact with a dog. Sally walked next to her mother when there was no dog in sight

but quickly became extremely distressed when she saw one. She tried to climb up her mother as the dog approached and wanted to be carried. When – due to Sally’s size and weight – this failed, she tried to run away from the dog and had to be restrained by her mother.

Intervention

The worker and Sally’s family identified that she needed to be taught more adaptive strategies to follow when she saw a dog, and that these should be supported visually. Before direct work with Sally began, the worker made a number of visual supports. These comprised:

- a portable strip with four detachable images to show Sally what to do if she saw a dog. This would show Sally a strategy to use when she saw a dog and would help to lower her anxiety. It also gave the adult accompanying her something tangible they could give Sally to focus on.
- detachable images (black and white line drawings with words beneath) that showed “Walk”, “See a dog”, “Hold hands with...” and “Keep walking”. Although Sally used a printed word schedule at school it was felt that, as her anxiety level was particularly high when in the presence of dogs, she would need more concrete and visually clear instructions
- the “Hold hands with...” card had a space for a photograph of whoever she was walking with. This would give Sally additional information at a time when her anxiety was at its most extreme.

Copies of all visual supports, with photos of the appropriate people (her mother and father for home, the classroom staff for school), were shared with school so that the visual supports could be used across all environments to ensure that the strategies used to help Sally were consistent.

The worker began by introducing the portable strip to Sally at home to ensure that she understood the information on it. She then went out for a walk with Sally and her mother. The visual support at this time indicated that, if she saw a dog, Sally should hold hands with the worker. The worker had pre-planned the walk with a dog-owning colleague, to ensure that Sally would come into contact with a dog. When the dog appeared the worker showed Sally the portable strip and she held the worker’s hand. However, as the dog came closer, Sally became very agitated and began to run (exciting the dog, which strained at its lead) and the worker was unable to keep hold of her.

Following this, the worker restructured the visual supports to show Sally “holding hands and standing still by...” as it was clear that expecting Sally to walk away was unrealistic. This strategy was tested on a second walk and proved much more successful. Following the introduction of this restructured visual support, Sally was encouraged to complete a number of walks both at home and school with different adults.

Outcome

The family are now able to go out together as Sally has a strategy she can use when she sees a dog and, as a result, can tolerate being near to them. The school are now able to take Sally out and she can again join in school-based community activities. Over time, the “Hold hands with...” card, with a photograph attached, has been superseded by a generic image of an adult and child holding hands, as Sally is able to follow this strategy with any adult she is walking with.

Lee

Lee was a 6 year old child who lived with his mother when the team began working with the family. He attended a local special school, and had also recently started spending a few nights every month at a local residential short breaks service. At school, Lee used a static photo schedule (up to four photographs at a time). He took the photograph from the schedule and used it to independently transition to an area or task where he would match the photo to a corresponding image.

Lee was referred as his mother was having difficulties at bedtime. Though his mother had developed a clear routine preparing him for bed in the early evening (i.e. supper, bath, clean teeth, pyjamas on), Lee then played downstairs until he fell asleep on the sofa (usually between 10 and 11pm). He was then carried up to his own bed. If his mother took him to bed before he had fallen asleep, he refused to stay in his room and followed her back downstairs. Lee woke during the night each night. When he did so he went downstairs to find his mother or, if she was already in bed, went to her room and got into bed with her. As a result of this, Lee's mother had not had an unbroken night's sleep (apart from when he was at the short breaks service) for more than four years.

Intervention

The Family Advisory Worker and Lee's mother planned the intervention around Lee's pattern of overnight stays at the short breaks service. Direct work with Lee began four nights before he was due to go for a two-night stay at the short breaks service. This enabled his mother to commit to the work involved knowing that she could be able to catch up on sleep while Lee was attending the short breaks home. The short breaks service also committed itself to follow the new strategies when he was there.

Before the direct work began, and following consultation with Lee's teacher, the Family Advisory Worker made a number of visual supports. These were:

- a photograph schedule, similar to the one he used successfully at school, to reflect his existing bedtime routine, with the addition of a 'bed' photograph. This ensured that the majority of Lee's bedtime routine would remain the same and that he would only have to accept the introduction of one new element.
- a photograph of Lee in bed. This identified to Lee that the expectation was that he would get into bed to sleep (not play in his room).
- a transition pocket to be attached to the wall near Lee's bed with a 'bed' photograph on it. This was to help Lee with the transition from downstairs to his bedroom by carrying the photograph to his room and putting it in the pocket when he reached his bed.
- an A4 enlargement of the photograph of Lee in bed to put on his bedroom door, to reinforce to Lee to which bedroom he needs to go.
- multiple copies of the 'bed' photograph. These would be handed to Lee to redirect him back to bed if he left his room to go downstairs or go into his mother's bed during the night.

Copies of all visual supports – with the appropriate images – were made so that they could be used during Lee's stays at the short breaks service too, and the Family Advisory Worker liaised with Lee's key worker there to ensure that the intervention strategy and the use of the visual

supports would be consistent across both environments.

Discussing the case, the team felt that Lee needed a neutral person to take him to bed to break the strong routine he had built up with his mother. Therefore the Family Advisory Worker introduced the visual supports and worked directly with Lee for the first two nights, while Lee's mother remained downstairs.

Lee followed the schedule and used the visual supports well. At 7.30 p.m. he was encouraged to take the 'bed' photo with him upstairs and to post it in the pocket next to his bed. When Lee had settled in bed the worker remained on the landing outside his room. Whenever he came out of his room, she directed him back to bed by showing him another 'bed' card and taking him to his room, using minimal language. Lee eventually fell asleep in his bed at 1 a.m. The worker advised his mother that if Lee went into her room during the night she was to redirect Lee back to bed in the same way.

On the third night, Lee's mother was supported to take over and take Lee to bed herself. It was important that Lee did not begin to associate the visual supports with the worker, or to consider the worker as a visual prompt to go to bed, but rather understood that he should follow the visual instructions shown to him. Therefore although the worker was in the home, providing guidance and instruction for his mother, she remained out of sight of Lee, who did not know that she was there.

Outcome

Within two weeks of the intervention beginning, Lee was going to his own bedroom across both environments without issue and was generally asleep by 9 p.m. This has continued, and he now sleeps through the night about 75% of the time. His mother reported that the intervention has been a positive and empowering experience, as it has helped Lee and also allowed her time to herself in the evenings for the first time in years.

The parents' views

During 2007, the team completed 24 interventions working in the home or community with the child and family. Evaluation forms were sent out to all of these families and 18 completed forms (75%) were returned, relating to the work undertaken with 19 children. All of the evaluations were positive, and identified that all respondents strongly felt that:

- they were given time to discuss their concerns with the worker
- the worker acknowledged the importance of their perspective
- the support the team offered was beneficial to the whole family.

In addition, and with regard to the way in which interventions were carried out, all respondents felt that:

- the workers were sensitive to family values
- the family understood what the workers were doing and why
- the family felt supported by the worker when they took over the direct work with the child
- after the intervention, they felt confident to continue working independently with their child.

Parents commented specifically about the way in which the team had demystified the approaches used:

“The service (from) the ASD Family Advisory Team which most stands out for our family was the creation and implementation of schedules. When you are told you have an autistic child, after a while you start to read books about it, and each and every book tells you about schedules. However, such a simple idea was so difficult to actually start and make! (It was) so daunting! But never fear...the worker arrived with a full catalogue of images – all laminated – and a schedule ready to go.”

It had increased their understanding of their child’s ASD and their confidence to work with them:

“The work which she has done with me has enabled me to understand my child so much more, and made me really confident in helping him. This in turn is helping our whole family to benefit.”

“She was an amazing support at a time when the whole family needed it...I never felt my questions were irrelevant or stupid, and she allayed many fears and worries. It was a real pleasure to speak to someone who really knows about autism.”

“The help gave me a greater understanding of him and his needs. I know he now finds things a lot easier.”

In some cases helped the families to come to terms with the child’s autism.

“The Family Advisory Team worker gave me the support and confidence to come to terms with my daughter’s autism, and deal with the issues which I have now and will face in the future.”

Key issues

The case studies and the families’ responses highlight key issues we believe are crucial in making the service effective.

Parent/family – professional partnership

Research identifies the importance of family-centred partnership working (Dunst and Dempsey, 2007), indicating that working with families in such a model can improve their self-efficacy, reduce dependence and improve outcomes (Cunningham and Davis, 1985; Dale, 1996). The team strives to work in this way. In all interventions:

- The family and the worker identify the areas of work together.
- The family and the worker have explicitly identified responsibilities in the intervention.
- The work is undertaken at the tempo agreed by the family and the worker.
- The family and the worker jointly evaluate the intervention’s effectiveness.
- The family and the worker jointly identify when the work has been completed.

Working on the family’s issues

Dunlap and Fox (2007) discuss the importance of the family choosing which issues must be resolved, and which concerns have precedence. In the team’s experience, it has been vital that the issues addressed are those the family sees as priorities, and are achievable. Referring

agencies may identify a need for support with issues such as toilet-training – because it is not ‘age-appropriate’ that the child is still incontinent – when assessment indicates the child is not yet aware in this area, and where the family has other, more pressing priorities, such as getting the child to eat, or to sleep.

Supporting the family to work ‘hands on’ with the child as soon as possible

The benefits of modelling in parent training in the field of autism are well established (Kolko, 1984). Moreover, experience suggests that it is beneficial if family members work ‘hands on’, putting the strategies into practice with the child, as early in the intervention as possible. This

- clarifies for the family the role of the ASD Family Advisory Worker: they are there as an advisor and empowerer, not as a direct care giver
- clarifies the role of the family members: they are active co-therapists and partners, not passive recipients/consumers of services
- demystifies the strategies and tools being used
- prevents the child from associating the worker with the desired outcome (e.g. ‘I go to bed when the Family Advisory Worker is there’).

Working as part of a multidisciplinary team around the child and family

The team works closely with colleagues from a wide range of disciplines – educational psychologists, class teachers, ASD-specific advisory teachers, and community nurses. The use of the TEACCH model within the county to underpin services for individuals with ASD provides these professionals with a shared understanding of ASD, a shared value base, and a common language. This is helpful in enabling professionals to acknowledge the limits of their roles and competence, and in engaging in multidisciplinary problem-solving, focused on outcomes for the child and family as described by Lacey and Ouvry (1998).

Targeted responses

Belsky (1984) identifies three main sources of influence on parental functioning: their personal psychological resources, the child’s characteristics, and contextual sources of stress and support. Dore and Lee (1999) further identify that parental characteristics such as poverty, depression, and social isolation have been found to predict poorer outcomes with regard to parents learning to use new approaches with their children. Working to introduce consistent, structured approaches in the home can be both physically exhausting and mentally challenging. Family members need to be ready to undertake these interventions, and to have sufficient resilience to keep going. Experience over the past decade and more suggests that when families are in crisis, suffering burnout, or experiencing the impact of acute stressors other than their child’s autism – loss of employment, inadequate housing, having another child, experiencing physical or mental illness – they will not have the resilience and resources required to successfully work in this way. At such times, the team redirects families to more direct sources of formal social support, such as play schemes, home care or short breaks services.

This has led to some criticisms that the team does not offer equality of access to all families. However, experience indicates that attempts to introduce structured interventions in partnership

with families who do not have the physical, mental or emotional stamina required to carry them through are not only doomed to failure, but make the families perceive themselves more negatively than before. Though now aware of what could have a positive impact on their lives, they may remain unable to put this awareness into practice.

Introducing more direct support services in conjunction with the team's intervention can make a great difference, and may enable the family to address the child's behaviour. For example, in the case of Lee, the regular overnight stays at a residential short breaks service meant that his mother felt able to work on his sleeping difficulties, knowing she would get an unbroken night's sleep when he was at the residential home.

Clarity of function

The team has a clear remit to work with the families of children

- with a diagnosis on the autism spectrum,
- who benefit from structured teaching approaches
- where the intervention required is to deal with home/community based issues
- and where the family meets the county's service for disabled children's eligibility criteria.

As a result of this, there are situations where the team cannot get involved. These include those where families do not meet eligibility criteria; where the child does not have a firm diagnosis; where the child does not respond to structured teaching approaches; or where the presenting difficulties result from problems at school.

Again, the service has been criticised for its lack of universality, and many of the families and situations with which the team does not work would doubtless benefit from professional input. However, the team is very small, and even with its limited remit the waiting time for an intensive 'hands on' intervention can be up to a year. Furthermore, ring-fencing the team's role has allowed workers to develop their skills within their field of expertise, rather than endeavouring to be 'jacks of all trades'.

Concluding comments

Mesibov, Shea and Schopler (2005) identify the key fundamental values of the TEACCH programme to be:

- respect for the family's knowledge of their child
- respect for the family's individuality
- respect for the love that family members have for their children with ASD
- respect for the resilience that family's show under great pressure
- respect for the contributions families make
- respect for the family's needs for accurate knowledge and effective support

These same values underpin the work that the ASD Family Advisory Team carries out in Northamptonshire. We believe the team provides a model of service delivery that could be

transferred to other settings in the United Kingdom and elsewhere, and that support and advice of this kind should be a fundamental part of the range of services for families with a child or children on the autism spectrum in all areas.

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