Developing effective partnerships with parents to improve outcomes for children with autism and their families

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Introduction

Successful partnership working with families has long been identified as a vital component of effective programmes across education, public health and social care (Early and GlenMaye, 2000; MacKean et al., 2005; Milbourne, 2005). Where families include children with special educational needs and/or disabilities (SEND), the importance of working in partnership is increased (Dempsey and Keen, 2008; Pelchat and Lefebvre, 2004) and service providers and agencies are increasingly required to endeavour to work in partnership with families – for example (in England) through the joint development of education, health and care plans for children with SEND (Department for Education, 2014).

The importance of effective specialist support is further heightened in the case of families that include children with autism. Reasons for this include:

- the elevated stress and anxiety that autism can cause within families (Koegel et al., 1992)
- the ineffectiveness of typical parenting strategies (Siegel, 1996)
- professionals’ ignorance/lack of understanding regarding autism (Preece and Jordan, 2007a; Rhoades et al., 2007).

This paper draws upon my research over the past 15 years – and professional practice over an even longer period – to consider the support and educational needs of such families.
**The impact of autism on the family**

Autism is a pervasive and lifelong developmental condition, affecting at least 1% of the population (Baird et al., 2006). It is characterised by differences and difficulties in social interaction and social communication, the ability to think and act flexibly and the perception and management of sensory stimuli (American Psychiatric Association, 2013). There is overwhelming evidence that the presence of autism can significantly affect families, causing greater parental stress than other disabilities (Wolf et al., 1989) and impacting not only on the parents but on siblings (Petalas et al., 2012), the wider family (Margetts et al., 2006) and the individuals with autism themselves (McCabe et al., 2013; Preece and Jordan, 2010).

The levels of stress, isolation and stigma that families experience are subject to a range of variables that can variously act as mediators and moderators. These include:

- housing (Langworthy-Lam et al., 2004)
- family finances and employment status (Cidav et al., 2012; Stoner and Stoner, 2014)
- the child and family’s experience of and relationship with school (Whitaker, 2007)
- the availability of informal social support (from family, friends and neighbours) (Boyd, 2002)
- the availability of and access to professional or formal’ support services (Tarleton and Macaulay, 2002).

Families of children with autism receive more limited levels of informal social support than other families (Preece and Jordan, 2007b). Therefore effective professional support – from educators, health professionals and workers in the field of social care – is of particular importance to these families.

**Rationale – and a few words about methodology**

I worked as a practitioner – first working in services for disabled children and their families, and later managing and developing ‘autism-friendly’ services – for over 30 years (Preece, 2009). For most of my adult life, my answer to the question ‘What do you do?’ was ‘I work with children with autism’. It is crucial to
me that the priorities and viewpoints of children with autism and their families are sought, heard, listened to and acted upon. I believe that research into the experience and needs of those living with autism – and practical support services offered to them – must take account of the differing experiences and situations of different families and family members. Research should seek to inform practice and identify ways to improve families’ lived experience. To do this, such research may utilize whatever methods best shed light upon the specific research questions being addressed: qualitative, quantitative or mixed.

This paper draws on previous research undertaken over many years regarding the needs of families and their experience of support, and is adapted from a number of previous publications. A range of research methods, both qualitative and quantitative, were used to address the foci of these studies. Information about these publications is briefly summarised in Table 1 below.

**Models of partnership working**

A number of models have been developed, and many books written, regarding ways that professionals can work in partnership with and support families in need to improve child outcomes. Some are generic, such as the ‘Family Partnership Model’ used to underpin the UK government’s Sure Start initiative (Cunningham and Davis, 1985; Davis and Meltzer, 2007) or Dunst et al.’s family systems intervention model, informing practice in US contexts (1988). Some are specifically focused on the needs of families that include children with SEND (Dale, 1996; Turnbull et al., 2014).

Working with partnership with parents is also an integral part of many autism-specific programmes: good examples of these include the Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) program, developed at the University of North Carolina at Chapel Hill (Mesibov et al., 2005), and the Social Communication/Emotional Regulation/Transactional Support (SCERTS) model developed by Prizant et al. (2003) developed at Brown University, Providence RI. Specific models of parent training have also been developed, such as the UK National Autistic Society’s ‘EarlyBird’ programme (Shields, 2001).
Table 1  Previous research on which this paper is based

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<th>Publication</th>
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<td>Preece, 2000</td>
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<td>Small-scale survey (n=18) of families using services via semi-structured questionnaire.</td>
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<td>Preece &amp; Jordan (2010)</td>
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<td>Whitaker &amp; Preece (2013)</td>
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<td>Preece (2014a)</td>
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Scrutiny of the various models and programmes in existence identifies that they share features in common, and that they borrow ideas from others. The SCERTS model, for example, uses aspects of at least 4 other approaches (Autism Speaks, undated) (for the record, these are Applied Behaviour Analysis, TEACCH, Floortime and Relationship Development Intervention); while TEACCH includes both behaviourist and cognitive components, and increasingly is used alongside interactive approaches (Howley, 2013).

Numerous variables impact upon each family situation. In addition to the practicalities of housing, employment and access to support, there are other factors such as culture, location, beliefs and family structure (to name but a few). No two families are alike. Equally importantly, autism is a spectrum condition – different individuals on the spectrum can be very differently
impacted within the domains that comprise the condition. No two individuals with autism are alike. As a result it would be foolish to expect any one programme or approach to be a panacea for all.

Moreover, programmes and services are not provided within a vacuum. Professionals’ activity and practice is bounded by myriad constraints: eligibility criteria and gatekeeping processes, staff availability and other demands on time and budgets. Therefore families’ accessing support is also affected by issues such as practitioner understanding and awareness (Preece, 2007a), waiting times, child care problems and intrusiveness (Birkin et al., 2008; Ingersoll & Dvortcsak, 2006; Whitaker, 2002), proximity to services (Koegel et al., 2002) and availability of funding (Preece, 2014b).

**Examples of partnership working**

In this section, I offer two vignettes which present examples of interagency partnership working with parents in the geographical area where my research was conducted: a local authority in the East Midlands of England. These vignettes are separated by time (the first took place 10 years before the second), by location (they took place in different towns) and by personnel (different professionals and families were involved).

Nonetheless there are factors which are constant between these examples. Over a 20 year period, from the late 1980s until the election of the coalition government in the UK in 2010, a range of autism-specific provision was developed in this local authority, across health, education, social care and voluntary sector providers (Preece, 2008). Included within these services was an Autism Family Advisory Service, which provided support, advice and training to families (Preece and Almond, 2008). These various services were underpinned by the use – across agencies and sectors – of the TEACCH approach (Mesibov et al., 2005) as well as other complementary approaches such as ‘Social Stories’ (Gray & Garard, 1993). Professionals trained in these approaches included teachers (in mainstream and special settings), educational psychologists, speech therapists, social care professionals, nurses and doctors.
Example 1: Partnership between family, school, Speech and Language Therapist and Autism Family Advisory Service (adapted from Howley et al., 2001).

Joe
Joe was a young man with autism and severe learning difficulties. He transferred from a mainstream school to a specialist autism classroom at the age of six. Much of his conversation was echolalic or focused on his interests. Though socially interested he preferred adult company and his social interaction was immature. He found it difficult to complete activities independently. He had problems regarding organisation and sequencing. He could not follow verbal directions and was prone to temper outbursts if he became confused.

When he transferred to the specialist classroom, he quickly became familiar with the general layout of the classroom and began to predict activities in designated areas. The ‘quiet room’ was important to him as he liked to spend time alone. He learnt to ask to use this area and was offered it as a choice during the day. He had a ‘visual schedule’ (Mesibov et al., 2005) which used symbols, arranged top to bottom, to identify what would be happening. This reduced his anxiety about what would be happening next.

Going to the local shops was a community activity undertaken at school. This was a particular source of anxiety for him, so time was spent developing a shopping routine that he could understand. This routine was supported by the use of visual information: symbol ‘shopping lists’ were introduced to help him understand shopping trips.

Joe also had difficulty waiting for activities to occur, or for his turn in a conversation. Visual supports to indicate ‘wait’ and ‘sit quietly’ were successfully introduced in the classroom; and – in collaboration with a speech and language therapist - a number of key phrases were introduced to reinforce his understanding, e.g. ‘stop’, ‘kind hands’, ‘good waiting’, ‘good work’, ‘first… then...’.

As Joe became more independent in the classroom, concerns were raised by his parents about his behaviour at home. The family contacted the family support service and an initial assessment identified the following areas of concern:

- Joe’s reliance on adults to occupy him at home
- his anxiety about shopping trips, and the impact of this on the family
- his socially inappropriate behaviours – e.g. interrupting others and temper outbursts.

Intervention
The family advisory worker worked alongside the teacher to identify ‘what worked’ in the classroom. These strategies were then transferred to Joe’s home.

Introduction of a schedule
A symbol schedule identical in format to that used in school was introduced at home on a notice board in the kitchen. The schedule identified mealtimes, bath and bedtimes, independent activities and household tasks.
Shopping
Joe was observed on several shopping trips both at a local supermarket and in the town centre. He found these trips very difficult to cope with and became very anxious. To provide him with continuity and consistency, the shopping routine used at school was transferred to home. He was given a symbol card to take to the supermarket - indicating the item(s) he needed to buy – and a favourite activity would be scheduled for his return. As longer shopping trips were most difficult, a hand-held visual support was developed to clarify how long shopping would last.

Reducing socially inappropriate behaviours
A ‘quiet corner’ was introduced at home, similar to the one in the classroom. This contained a soft chair, books and video player. A visual cue was used to direct Joe to the area when necessary. ‘Wait’ and ‘sit quietly’ cards were introduced at home to help Joe understand when it was inappropriate for him to interrupt and what to do instead. Whenever he used inappropriate methods to gain adult attention he was shown the relevant card. The functional vocabulary of key phrases was also transferred from home to school.

Outcomes
After a few months, during which time the family were supported to use these strategies at home, Joe was more independent around the house and his mother was able to leave him with others without him becoming distressed. He used his visual schedule effectively and could increasingly recognise when he needed time alone. He particularly liked his quiet area and would go there without prompting.

He became able to accompany his family on short shopping trips; and the frequency of inappropriate behaviours reduced as he understood what was expected of him, and the sequence of daily events. His mother stated that, in addition to providing practical support, the intervention improved the whole family’s understanding of Joe’s autism and helped them come to terms with his condition.

Example 2: Partnership between family, Autism Family Advisory Service, school and short breaks (respite care) provider1 (adapted from Preece and Almond, 2008).

Lee
Lee was a 6 year old child who lived with his mother, a single parent. He attended a local special school, and had also recently started spending a few nights every month at a short breaks (respite care) 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.

Help was sought as his mother was having difficulties at home, particularly at bedtime. Though his mother had developed a clear early evening routine, getting Lee ready for bed (supper, bath, clean teeth, pyjamas on), he then

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1 Short breaks/respite care refers to services that provide short breaks – ranging from 1 night to several nights at a time – to families of children with SEND. The child will spend time either in a residential children’s home (employing care staff) or in a specialist foster home. In this case the short breaks provider was a residential children’s home.
played downstairs until he fell asleep on the sofa. This was usually between 10 p.m. and 11 p.m. His mother then carried him upstairs to his bed. If he was taken to bed before he had fallen asleep, he refused to stay in his room and followed his mother back downstairs. Lee woke during the night each night. When he did so either went downstairs to find his mother or – if she was already in bed – he 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 or slept without her son in her bed for more than four years (apart from the few nights a month Lee spent at the short breaks children’s home).

**Intervention**
The Family Advisory Worker and Lee’s mother planned the intervention around Lee’s pattern of overnight stays at the short breaks provider. Direct work with Lee began 4 nights before he was due to go for a 2-night stay at the short breaks service. This helped his mother to commit to the work involved, as she knew that she could catch up on sleep while Lee was attending the short breaks provider. The short breaks provider also made a commitment to adhere to the identified bedtime strategy when he was there.

The Family Advisory Worker met with Lee’s teacher, and observed Lee in the classroom. Following this consultation, she made a number of visual supports to be used at home and at the respite care children’s home. These comprised:

- a photograph schedule. This was similar to the one he used successfully at school and reflected his existing bedtime routine, with the addition of a ‘bed’ photograph. This ensured that the majority of Lee’s bedtime routine remained the same, and that he only had to accept the introduction of one new element.

- a ‘bed’ photograph. This was a photograph of Lee asleep in bed. It clarified to Lee that the expectation was that he would get into bed to sleep.

- a transition pocket. This was attached to the wall near Lee’s bed with a ‘bed’ photograph on it. This was to help Lee transition from downstairs to his bedroom by carrying the photograph to his room and putting it in the pocket when he reached his bed – the same way he transitioned between activities in the classroom.

- an A4 enlargement of the photograph of Lee in bed. This was put on his bedroom door to reinforce to him which room he should go to.

- 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 the visual supports – with relevant images – were made so that they could be used during Lee’s stays at the short breaks service as well. The Family Advisory Worker liaised with Lee’s key worker\(^2\) there to ensure that the intervention strategy and the use of the visual supports would be consistent across both environments.

It was felt by Lee’s mother and the professionals that Lee needed a ‘neutral’ person to take him to bed, in order to break the strong routine he had built

\(^2\) A ‘key worker’ identified is an identified staff member at the short breaks service. They act as the main point of contact with the family and with other professionals regarding the child with SEND.
up over the years with his mother. Therefore it was the Family Advisory Worker who introduced the visual supports and worked directly with Lee for the first two nights. Lee’s mother remained downstairs. Lee followed the schedule and used the visual supports well; and 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. After Lee had settled in bed the worker remained upstairs outside his room. Whenever he came out of his room – which was frequently – 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. However on both nights Lee remained asleep until the morning.

On the third night, Lee’s mother was supported to take over, and to 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. Therefore although the worker was in the home and provided guidance and instruction for his mother, she remained downstairs and out of sight to Lee, who did not know she was there.

When Lee went to the short breaks service, staff at the home followed the same strategy, using the visual schedule to transition him to bed and redirecting him back to bed as necessary with a ‘bed’ card.

**Outcome**

Within two weeks of the intervention beginning, Lee was going to his own bedroom without complaint, both at home and at the short breaks provider, and he was generally asleep by 9 p.m. Six months after the intervention, he slept through the night about 75% of the time. His mother felt that participating in the intervention was positive and empowering, as it both helped Lee and also allowed her time to herself in the evenings for the first time in years.

**What helps when working in partnership with the parents of children with autism?**

The studies I have undertaken within this field have identified a number of consistent key aspects of effective family-centred multi-agency working with parents. These comprise:

- worker attributes, including their professional competence
- the development of meaningful partnerships, and working to a shared agenda
- supporting the family to develop their skills
- appropriate, individualised support.
Workers’ attributes, including professional competence

"The people...they really knew what they were talking about. They seemed to really understand autism...they seemed very willing to chat to you about everything, and would be willing to try anything that would be suitable for your child."

Peeters and Jordan (1999) identify a range of personal attributes that they feel are essential for those working in the field of autism. These include imaginativeness, adaptability regarding communication and social interaction styles, teamwork, flexibility and humility– as well as being ‘bitten by the bug of autism (p86).’ As well as competence in their profession, appropriate (and preferably shared) training in autism is also vital. Shared training leads to a shared understanding of autism and the development of a shared value base (Howley et al., 2001). This allows professionals

- to better understand each other’s perspectives, experience, skills and constraints
- to acknowledge the limits of personal and professional competence
- to engage in multi-professional problem solving.

and facilitates the development of practice focusing on outcomes for the child and family (Lacey and Ouvry, 1998).

Meaningful partnerships and working to a shared agenda

Working in meaningful partnership with families can improve their quality of life and self-efficacy, reduce dependence on professional support and improve family and child outcomes (Cunningham and Davis, 1985; Dale, 1996). Such partnership working is not easy. Potential barriers are many, at both institutional and personal levels (Lester et al., 2008; Sloper, 2004) and all partners must strive to be open and honest in their interactions, with a common focus on outcomes for the family and child. It must be noted also that parents and other family members may share – in a milder form – some of the thinking styles and other characteristics of autism. The presence of ‘autistic-like traits’ in undiagnosed family members is well documented ((Sasson et al., 2013): problems with flexibility or some aspects of social interaction and communication can be challenging for all parties.
Dale (1996) emphasises the importance of acknowledging and understanding the family’s perspective; and Dunlap and Fox (2007) identify the importance of enabling the family to identify which issues need to be resolved and which concerns take precedence. The professionals interviewed within these studies acknowledged that it was essential that the issues addressed were prioritised by the families – and were realistic and achievable. An example (from Preece and Almond, 2008): a 5 year old was referred by a professional to the Autism Family Advisory Service. The professional was concerned that the child was still incontinent and requesting support with toilet training. However, discussion with the family and assessment of the child with autism swiftly identified that the child was not yet ready to be toilet trained. Moreover, the family felt that there were far more pressing issues, such as getting the child to eat or to sleep at night. These latter issues – which the professional had not been aware of – were addressed as priorities.

**Supporting the family to develop their skills**

It is vital that families are supported to develop their skills through appropriate parent education. This can be done in a number of ways, including the provision of parent training classes and through direct modelling of skills.

*Training*

A key facet of partnership working with families is the sharing of knowledge, of ensuring that parents and professionals alike hold the same understandings, giving them a shared contextual framework and a common language (Preece, 2014b). Providing information to parents through training sessions fulfils multiple functions: as well as sharing knowledge, it gives potentially socially isolated families opportunities to meet with others and to develop friendships and supportive networks.

What do families need to know? The same things that professionals working with individuals with autism need to know:

- accurate information about autism
- positive strategies for managing behavioural issues
- effective ways of dealing with crisis situations.
Accurate information about autism
Parents need to know what comprises current ‘good practice’ in autism. The internet is a minefield of inaccurate information and voodoo approaches, and it is incumbent on competent professionals to provide families with our best understanding of what autism is and what works or helps. Research identifies that educating parents about autism is valued (Whitaker, 2002), that it reduces parental stress (Brookman-Frazee & Koegel, 2004) and that its benefits maintained over time (Koegel et al., 2002).

Positive strategies
The survey of families in this local authority identifies that understanding and managing behaviour was a significant issue for 88% of respondents (Preece & Jordan, 2007a). A key tool to supporting socially adaptive and appropriate behaviour is positive behavioural support (PBS) (Johnson et al., 2006). While information about PBS is typically included within more general training courses, research undertaken (Preece, 2014b) suggested that it can be helpful to provide specific training regarding understanding and managing behaviour.

Crisis intervention
Sometimes the behaviours presented by the child with autism required parents to physically intervene to keep the child or others safe; and a subset of parents were reporting that they were having to restrain their children multiple times per week.

“*He gets very distressed by change in routine. He throws himself around the room or furniture, and kicks and sobs when we try to explain things. He won’t listen or accept any changes.*"

“*He can get very distressed and is very aggressive towards his mother and sisters.*"

Intervening in such ways without guidance regarding either safe handling techniques or alternative management strategies is clearly unsafe. Providing training in crisis intervention techniques, alongside PBS approaches, was beneficial to such parents, and reduced the use of physical interventions within these families (Preece, 2014b). Knowing that they could safely physically intervene if necessary gave parents the confidence to seek to identify the
functions of their child’s behaviour, and helped them to develop their ‘toolbox of strategies’ (Charman et al., 2011).

Modelling
As well as group training, the provision of direct one-to-one modelling is important in developing parents’ skills and confidence. The use of modelling in parent training in autism is long-established (Bristol, 1984; Kolko, 1984). Taking an active role within an intervention minimises stress and improves parent/professional interaction (Beresford, 1994) as well as increasing parental self-efficacy (Turnbull et al., 2014). Professionals and parents interviewed identified the benefits of supporting family members to work ‘hands on’ using the strategies as soon as possible. This helps family members see themselves as active co-therapists and partners (not as passive recipients of services and demystifies the strategies being used (Preece and Almond, 2008).

Appropriate, individualised support
There is no ‘one size fits all’ approach in autism and professional support for and partnerships with families must be individualised to take account of their strengths, needs and situations. Some families may have a limited understanding of autism, while others may be extremely well informed (which can be challenging for professionals). Some families may be resilient, while others may be highly vulnerable. Professionals must have insight into and empathy with the family’s experience, as well as that of the child (Whitaker and Preece, 2013).

“I would like the staff to understand who my daughter is and what it feels like to be her.”

Belsky (1984) identifies 3 main sources of influence of parental functioning: their personal psychological resources, the child’s characteristics, and contextual sources of support and stress. Dore and Lee (1999) identify that poverty, social isolation and depression are predictors of poorer outcomes with regard to parents using new approaches with their children. Therefore interventions that require proactive parental involvement must be undertaken when family members are ready to do so, and when they have the physical and psychological
resilience to work on the identified issue. Such interventions must take place within a wider supportive context of service provision, in which more direct sources of support (child-minding, play schemes, domiciliary care and short breaks/respites) are also available.

**Final thoughts**
Mesibov *et al.* (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

I would argue that these values are crucial for any professionals working with children with autism and their families, and feel that they underpin the parent-professional partnerships that have been discussed in this paper. Life is hard for individuals with autism and their families. Without effective partnership working, the challenges faced by these individuals – as well as those facing the professionals supporting them – are made substantially, and needlessly, harder.

This paper is dedicated to the memory of both Dr Penny Lacey and Terry Arnold, who taught me so much about effective partnership working.

**References**


