

Treasury Review of Disabled Children's Services



September 2006

The National Autistic Society (NAS) is the leading charity for people with an autistic spectrum disorder (ASD) in the UK. It has a membership of 15,000, a network of around 70 branches, and 90 partner organisations in the autism field. The NAS exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services, appropriate to their needs. The NAS welcomes the Review of Disabled Children's Services and values the opportunity to respond to it.

This response contains many examples of good practice. Often these are isolated examples of services which are leading the way in the development of high quality, effective services for children and young people with autism and their families and which could be replicated across the country.

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Autistic spectrum disorders (ASD)

Autism¹ is a lifelong developmental disorder that affects the way a person relates to the world around them. People with autism experience difficulties with social

¹ In this submission the terms autism and autistic spectrum disorder (ASD) are used to refer to a group of disorders including classic autism, Asperger syndrome and high functioning autism.

interaction, social communication and imagination – known as the 'triad of impairments'.² It affects an estimated 535,000 people in the UK, and one in 110 children has an autistic spectrum disorder (ASD). As such, everybody working with children should expect to work with children on the autistic spectrum.

The autistic spectrum includes children with severe learning disabilities with little or no verbal communication, through to those with an average or high IQ, including those with Asperger syndrome. However, the difficulties faced by people with high functioning autism or Asperger syndrome may be no less profound than for those with learning disabilities. It is important that people across the spectrum receive the support and services they need.

The first economic study of the UK costs of autism estimated the average additional lifetime cost to be £2,940,538 per person.³ These long-term costs can be significantly reduced by investment in support services to enhance the possibility of social inclusion and independent living.

Changing nature of disability

As highlighted in the terms of reference for the Review, the profile of disabled children is changing. As the number of children with disabilities such as ASD increases, these changes need to be reflected in practice. For example, currently Disability Living Allowance application forms are not suited to the needs of people with ASD, who have to fit descriptions of their condition around questions which are more suited to people with physical disabilities.

Following recent guidance published earlier this year for Directors of Adult Social Services by the Department of Health⁴ there will have to be clarity over which team or manager is responsible for services for clients with autistic spectrum disorders, and their needs are considered on an individual basis. This is a significant recognition of the increasing prevalence of ASDs and the naming of team or manager with specific responsibility for ASD sets a precedent which could very usefully be mirrored by children's services teams.

² Wing, L. and Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, Vol. 9(1), pp. 11-29

³ Knapp M. and Jarbrink, K (2001) The economic impact of autism in Britain. *Autism* vol 5(1), pp. 7-22. This figure represents the average additional lifetime cost of a person with autism and an accompanying learning disability. The figure for a person with high-functioning autism is estimated to be £784,785

⁴ DH (2006) Guidance on the statutory role of the chief officer post of the Director of Adult Social Services; Best practice guidance on role of Director of Adult Social Services

ASD and ethnicity

There is some limited evidence that children from certain ethnic minority groups may be overrepresented amongst children with a diagnosis of ASD⁵. However, recent research from the DfES suggests that among other ethnic groups there is a lower rate of identification of ASD than among the white population⁶, and this may be because it is more difficult to identify communication impairments for children with English as an additional language, and because some communities are less likely to access healthcare at an early stage. Further work needs to be done to investigate the incidence of autism among minority ethnic communities.

Services to support families from black and minority ethnic communities whose children have autism are extremely scarce. There is little awareness of autism among some minority ethnic communities, and some languages do not have a word for autism, which can cause confusion in relation to diagnosis, often with mental health or learning disability terms used instead. Some of the developmental milestones which are used as a basis to identify developmental delays may also be cultural-specific. For example, in some cultures toilet training may be "normal" at 18 months, whereas in others children aged five may not yet be expected to be toilet-trained. This can cause difficulties when trying to identify developmental delays.

The NAS does outreach into communities within London to raise awareness and provide information, and runs training for professionals, providing autism awareness training to equalities and diversity officers in PCTs, and providing equality and diversity training to ASD-specific professionals. However, to our knowledge there are virtually no other projects of this nature around the country.

- Research should be commissioned and funded into the incidence of ASD among different communities
- Appropriate services should be developed to raise awareness and provide information and family support to families from black and minority ethnic communities
- Training in autism should be provided for professionals working with families from black and minority ethnic communities, and autism professionals should receive equality and diversity training

Early intervention

The professional and scientific consensus on the benefits of early intervention for children with an ASD is strong. The National Autism Plan for Children (NAP-C), a report from a multidisciplinary expert working group, recommends that all

⁵ Gillberg, C., Steffenburg, G., Borjesson, B., Andersson, L., (1987) Infantile autism in children with immigrant parents: a population based study from Goteborg, Sweden, *British journal of psychiatry*, 150, p 856-858; Goodman, R., and Richards, H. (1995) Child and adolescent psychiatric presentation of second-generation Afro-Caribbean's in Britain, *British journal of psychiatry*, 167, p 362-369

⁶ Lindsay, Pather and Strand (2006) *Special educational needs and ethnicity: issues of over- and under-representation* DfES Research Report 757, DfES: London

children receive a minimum of 15 hours of autism-specific interventions each week.⁷ The only economic analysis of autism in the UK to date highlighted that, from an annual total cost of autism of at least £1 billion, only 7% was spent on education. The authors concluded that 'evidence suggests that even moderate increases in educational provision could potentially result in major savings in later living costs.'⁸

During the 1990s the Robert Ogden NAS School in Yorkshire worked in partnership with the local authority and took eight children aged four and five who had diagnoses of autism. The children attended the school for two or three years (one girl for six years) and after this all the children were able to attend and remain in mainstream schools. One of the children later went to university and became a graphic designer. This demonstrates how a local authority can act with foresight to achieve the best outcomes for children and save money in the long term.

This example demonstrates how putting effective specialist support in place at an early stage can maximise children's chances to be able to be integrated into mainstream provision and go on to lead successful lives. However, we are seeing a trend in the opposite direction as children are rarely referred to our schools now before the age of eight. Increasingly a greater proportion of the children attending our schools are at the more able end of the spectrum and also have complex challenging behaviour and mental health problems. Often these children have been failed by a number of schools, both mainstream and special, and an NAS autism-specific school is seen as the last resort. Much work has to be done to undo the effects of past negative experiences before positive steps forward can be made. In many cases had these individuals had specialist support in the first place, they may well have been able to move from our schools into mainstream.

- Central and local government should invest in early intervention and preventative services as a priority to ensure long term cost savings and the best outcomes for children

The evidence base for the relative efficacy of ASD-specific interventions is weak. Few intervention methodologies have been subject to rigorous objective assessment against scientifically-credible criteria. Research into causes, costs and effective interventions for autism needs to be prioritised by Government. The Autism Research Co-ordinating Group, led by the DfES, stated in its first annual report that:

"The quest for a robust evidence base to inform practice is a priority. Until we have stronger evidence in support of, or invalidating, interventions, individuals with autism may be vulnerable to experiments that at best are harmless but costly and inconvenient, and at worst may be positively harmful. In addition, differing opinions

⁷ NIASA (2003) *The National Autism Plan for Children*, NAS: London

⁸ Knapp M. and Jarbrink, K (2001) The economic impact of autism in Britain. *Autism* vol 5(1), pp. 7-22.

about specific educational approaches are often played out in disputes between parents and local authorities, which divert energy and resources away from the primary objective of providing appropriate education for individual children.”⁹

- Research should be commissioned and funded into the relative efficacy of different autism interventions

Specialist support for universal services

NAS schools work with mainstream and local authority special schools to share resources and expertise. They have been able to provide outreach support to other schools, mainly negotiated on the basis of one individual at a time, rather than broader contracts. In Harrow, Radlett Lodge NAS School was able to successfully support a child with ASD at a local authority special school. This arrangement prevented the family going to tribunal to get a place at Radlett Lodge School. Staff from the special school were also able to spend a week at Radlett Lodge to gain further expertise and understanding of ASD, thereby enabling the expertise to be available to a wider group of children. Other NAS schools have been able to offer opportunities for staff from mainstream and non-autism-specific special schools to be able to do placements with them. However, this is becoming more difficult to arrange as NAS schools see an increase in the complexity of needs demonstrated by children who are placed with them, and have fewer resources to be able to support visitors on placements. The recent Ofsted report on provision for children with learning difficulties and disabilities stated that specific training from specialist teachers and professionals from other agencies was particularly effective in raising expectations and providing more effective teaching¹⁰. However there are concerns that specialist services are being eroded as a result of delegated SEN funding from local authorities to schools. Ofsted report that “Where funds were delegated, it disadvantaged groups of pupils with complex special needs who did not have access to specialist support because funds had been used for other purposes.”¹¹

A number of children who are placed at NAS schools visit local mainstream schools where extra subject expertise is required, for example where a child has considerable ability in maths. Where partnerships can be set up this can be an extremely effective arrangement, but in our experience, on the whole very few children are in dual placements. This is in part because of difficulties of negotiating and sharing funding (particularly for out of authority placements or when support workers from the NAS school provide support during the mainstream placement), and issues over who has legal responsibility for the child during placements.

⁹ Autism Research Co-ordinating Group (2006) *First annual report* DfES Research Report 787, DfES: London, p13

¹⁰ Ofsted (2006) *Inclusion: does it matter where pupils are taught?*

¹¹ Ofsted (2005) *Inclusion: the impact of LEA support and outreach services*

- Protocols need to be established to clarify legal responsibilities and financial responsibilities between services and facilitate the development of these services.

Statements

The current statementing system for children with special educational needs provides a welcome statutory duty on education services to provide the support described in the statement and clearly sets out a child's entitlements, and we would not want to see a review of the current SEN framework. However, many children do not receive the non-educational element of support specified in their statement. For example, according to a recent survey of autism and education, only 55% of children with autism receive the speech and language therapy outlined in their statements¹².

Where children have been assessed as being in need of particular forms of support, it is important that they receive that help, which might include transport, occupational therapy, mental health support, or social services support. The non-educational elements of a statement should be made statutory in the same way the educational elements are currently, and should be funded by the relevant agencies. This would ensure that a child's full needs are met.

- Non-educational elements of statements should be made statutory and be funded by relevant agencies

Exclusions

A recent NAS survey showed that one in five children with autism and one in four with Asperger syndrome has been excluded from school, many on more than one occasion. Children from black and minority ethnic backgrounds are more likely to have been excluded than their white peers. More than a third of children had missed a term or more of school, and one in ten had missed more than one school year over the past two years alone¹³. The most common reason given to parents for exclusion by schools is because the school does not feel able to cope with the child¹⁴. Many children are also excluded on an informal basis, which amounts to less favourable treatment under the Disability Discrimination Act, and is therefore illegal¹⁵.

- Stronger legislation is needed to ensure that children with SEN and disabilities cannot be excluded as a result of issues related to their disability.

All children have a right to education during exclusion, yet 71% of parents say their local authority have put no support in place for their children during exclusions, even though they are required to after 15 days. Where children are

¹² Batten et al (2006) *make school make sense: autism and education*, London: NAS

¹³ Batten et al (2006)

¹⁴ Barnard et al (2000) *Inclusion and autism: is it working?* London: NAS

¹⁵ Batten et al (2006)

able to access services, these are often inadequate and staff often lack understanding of autism.

- Monitoring should be undertaken of whether local authorities fulfil their duties to provide education to children who have been excluded.
- Tutors should receive training in working with children with ASD

The population of children who attend our schools is changing, with a higher percentage of older, more able children with very challenging behaviour and mental health problems. At the NAS Robert Ogden School in South Yorkshire 30 per cent of pupils have been permanently excluded from both mainstream and special schools before they come to the school. To support these pupils, the school has established an 'Inclusion Resource' at Key Stages 3 and 4. Each pupil is given a personalised 'inclusion' timetable which enables them to negotiate their access to learning groups, or particular teachers with whom they feel comfortable. There is not an expectation that these pupils will attend all classes with their peers. Each pupil has an individual inclusion target each week, for example to attend an after school club. Pupils have been able to build up their tolerance of group learning, and have a personalised learning programme and their own space when they choose to use it.

Transition

Transition to adulthood is a critical time for young people. It is a time of great change and uncertainty, which is particularly difficult for young people with autism. Yet, an NAS survey revealed that only 53% of young people were issued with transition plans during their education, falling to just 34% of students in mainstream schools¹⁶. People in the transition age group (16-24 years) are significantly less likely to be able to access the support services they need.¹⁷ The two areas where the lack of services was most profound were play and leisure and housing. Only 43% of respondents felt that there were appropriate play and leisure facilities in their local area for the person they care for to use. Only 28% of respondents in the 16-24 age group had ever discussed current or future housing options with a professional. This demonstrates that housing is still not prioritised in transition planning. Although the involvement of adult social services is crucial to the viability of a transition plan, they are involved in the planning of only 17% of cases¹⁸.

There is a clear need for multi-agency transition planning from the age of 14 years. Staff who work in what is currently the Connexions service can play an important role in helping individuals to manage transition, however a lack of autism awareness limits the level of support available. The NAS would like training for these advisors to be tiered, with a regional officer trained in autistic spectrum disorders to advise colleagues.

¹⁶ Batten et al (2006)

¹⁷ Broach et al (2003) *Autism: Rights In Reality*, NAS: London

¹⁸ Batten et al (2006)

- Transition planning must start early and involve the full range of agencies who are or will be involved with a young person, including adult social services, housing services and people with expertise in autism

Only 6% of people with autism, and 12% of people with Asperger syndrome, are in full-time paid employment. The following example from a college student who uses NAS services demonstrates how, as with early intervention, effective planning and support at transition and access to high quality intensive services can help people with autism gain greater independence and may reduce the need for support later on, as well as enable them to access employment:

"I moved from Brighton to Manchester in 1998. I moved into the NAS residential service because I was not getting on with my parents. I was aware of Asperger Syndrome but did not understand it or how it affected me. I spent three and a half years in the residential service where I received round the clock support. During my time there I went to college (I did childcare and other care related courses). I learnt how to get up, took more care of my personal hygiene, became more confident and I become more of a chilled out person.

"I moved out in July 2001 to a supported tenancy in the local area. I developed more independent living skills and got a job helping people use public transport. I also did a hairdressing course at college. Gradually I didn't need support workers staying over and not as many hours of support.

"I built up my confidence to then move to my own flat where I currently live. My outreach support has been reduced to 10 hours a week; this is all I need now. Even though I am a lot more independent and confident I still need help with cleaning my flat and having someone I trust to talk about private matters and things that help me get on in the world. Over the years I have increased my social circle and my skill in communicating, I have a close knit circle of friends around me."

Extended schools

According to research by the NAS, when parents were asked where their children were not getting support to access school life outside the classroom, breakfast and afterschool clubs came top of the list. 44% of parents say their child has not been able to take part in activities before or after school, where they are provided. Children in autism-specific bases were half as likely to be able to take part in such activities as children in mainstream schools, with only 22% being able to take part, compared to 54% in mainstream. Children in special schools were most likely to access these services, with 63% of children in autism-specific special schools participating in afterschool clubs¹⁹.

¹⁹ Batten et al (2006)

Children who have extra support to enable them to access the school day, such as learning support assistants, can often find it difficult to access extended school services because their support is only provided during school hours.

“I used to have this person who helped me during the football club. This person called Catherine who was 19 used to help me. When I got distracted I could chill out. She's gone to university now. I can't go to football club anymore.”

Transport provided by the local authority to enable children to get to school can be inflexible and prevent students from attending activities outside regular school hours.

- The needs of disabled children must be considered in the development of extended schools services, including the provision of support and transport services

CAMHS

A third of children with autism also have another clinically recognised mental disorder, and 16% have an emotional disorder. A quarter of parents report that their child has tried to harm or kill themselves.²⁰ Yet, there is a lack of CAMHS services for children with ASD or learning disability²¹, with evidence of certain services refusing to treat children with ASDs. This is often due to a lack of confidence and training among staff to work with children and young people with ASD.

Children with ASDs often have a complex range of needs. In some parts of the country a large proportion of the children requiring Tier 4 CAMHS services are children who have ASDs. There is a strong need for training of mental health professionals to work with children with ASD. There are examples of good practice such as where CAMHS services are linked to schools. Siblings of children with autism are also likely to require access to CAMH services.

- All CAMHS workers need to have understanding of autism, using a tiered model with some having more in-depth knowledge, and practitioners at a regional level having specialist training.

Social skills

Carers surveyed for the NAS report *Autism: Rights in Reality*²² identified social skills training as the form of support most valuable for the person they cared for. Although this result was consistent across all age groups, only 9% of respondents actually received this service.²³ With the changing nature of disability, and the increasing numbers of people diagnosed with ASD there is a

²⁰ Green et al (2005) *Mental health of children and young people in Great Britain*, ONS: London

²¹ HMSO (2003) *Every Child Matters green paper* The Stationery Office: London

²² Broach et al (2003) *Autism: Rights In Reality*, NAS: London

²³ Broach et al (2003) *Autism: Rights In Reality*, NAS: London

need to develop such services to meet the growing need. Social skills training are key in promoting independent living and social inclusion and can be a low level, low cost intervention. Social groups can also provide valuable opportunities for people to meet other people with autism, providing social support and reducing isolation, which research has shown can have a positive effect on mental health, and can help prevent families reaching crisis point.

Group member 1: *What's he doing here?* (New group member pointing at another group member)

Social group manager: *Why don't you ask him?*

Group member 1 to group member 2: *What are you doing here?*

Group member 2: *I've got Asperger syndrome. I'm here for the social group.*

Group member 1: *What! You've got Asperger syndrome? Really? I thought I was the only one in the world to have it. It's not very nice. I got kicked out of school.*

Group member 2: *I found it got easier as I got a bit older. You can learn to live with it.*

"I appreciate this social group so much. C still gets lonely at times but without this group things would be much worse. He was depressed and in hospital for four months at one point. Please let your organisation know how much your support is appreciated. I feel it is crucial to C's mental wellbeing."

Parent of a young man with autism

The Chester branch of the NAS is working with a local agency, Chester Crossroads, to set up social skills training locally, at very low cost. A speech and language therapist runs the sessions, accompanied by an assistant speech and language therapist and supported by staff from Crossroads. They have developed links with a chess club at a mainstream school which provides an opportunity for children, some of whom attend special schools, to socialise with other children who attend the mainstream school.

Ongoing research being carried out by the NAS with University College London looking at the outcomes for young people who attended NAS schools suggests that an individual's socialisation skills are the strongest predictor of their outcomes in the long term. However, in general service providers do not recognise that an absence of social skills often acts as a barrier to independence for people on the autism spectrum.

- Social skills training programmes should be developed across the country.

Family support

There are a range of programmes and services which can provide support for families, and which, if introduced at an early stage, may alleviate the need for

more costly higher level interventions at a later stage. These include schemes such as befriending projects, such as the one run by the NAS, and afterschool clubs. It is important that staff working on these schemes have an understanding of working with people with autism. The NAS Early Bird programme offers support and training to parents of pre-school training. An evaluation of the programme showed that following the programme parents became and remained less stressed, and children made accelerated progress with communication, daily living skills and socialisation²⁴. Schemes such as the NAS Early Bird Plus programme provide an opportunity for both a parent and a professional who works closely with a child (such as key worker or teacher) to train in autism following diagnosis, thereby maximising consistency for the child.

Family support workers

The National Autistic Society has a number of Family Support Workers (FSW) who provide valuable community-based support to children with ASD, their families and carers. An ASD FSW builds on the keyworker model and provides a signposting and pathway service, as well as practical support to families, particularly after diagnosis. It fills a common gap in post-diagnostic work by providing practical advice to parents on topics such as toileting, diets, sleeping, communication and other sensory issues that are particular to autism. A FSW is able to deliver national expertise at a local level, which includes home visits to enable the special needs for each child or family to be identified individually. The main benefit is its immediacy and the preventative nature of the assistance and advice given to families who are able to self-refer to the FSW. Referrals also come from colleagues in health, social services and education, with whom the FSW works very closely. In some cases the posts are co-funded by these agencies, although this is rare, and they may be based within local authorities. This also enables a database of children and young people with ASD to be established across a region which can inform authorities in their strategic planning of adult services. These models could be based at children's centres to provide an effective and accessible service within the local community.

A similar model is used by the ASD training and development team in Liverpool. The team is based on education outreach team model, but is much broader and includes speech and language therapy, occupational therapy, teaching and social work support. It is based within the local authority and funded by a range of services, and receives referrals from the Alderhey Children's Hospital following diagnosis. They offer Early Bird, help! and the help2 programmes (NAS family support and information programmes following diagnosis), working with schools, and run drop-ins for parents and courses for siblings. They have recently been working with fpa to develop an ASD-specific programme helping parents of children with autism to communicate with their children about issues of sexuality

²⁴ Shields, J., Simpson, A. (2004) The NAS Early Bird Programme: preschool support for parents of children with autistic spectrum disorder *Good Autism Practice* 5(2)49-60

and sex education. This is initially being trialled in the northwest with the aim of rolling it out more widely.

- Multi-agency teams with expertise in ASD should be funded and developed to provide effective post-diagnostic support, advice and signposting to families

The NAS welcomes the wider roll-out of the Early Support scheme across the country and to children aged up to five years old. Early Support has provided an effective model for the co-ordination of services for very young disabled children. It is important to recognise that for the model to be successful in supporting families, the key worker system must be part of a broader package of good quality services with knowledge and experience of ASD, and effective multi-agency working.

Ongoing research by the NAS with University College London suggests that people with the best outcomes as adults were often from those families who had access to a senior professional who had good understanding of ASD and of the local area, and were recognised and respected locally.

Respite and short break services

Respite services are a particular gap for families of children with ASD. There are often long waiting lists for short break schemes and respite care, and over 90% of short break schemes have waiting lists. Children with ASD account for almost a third of these waiting lists²⁵, often because of a lack of skills and training in working with children with ASD. The National Audit of Support, Services and Provision for Children with Low Incidence Needs identified a lack of family support and respite care, particularly ASD-specific respite options, as the biggest barriers to be addressed for families of children with ASDs²⁶. Failure to provide appropriate respite services can lead to families reaching crisis point, where they can no longer cope with their caring responsibilities, and request extremely costly residential placements for their children as a last resort. There is a need for services to be flexible to be able to support families at particular pressure points, such as family illness. The Daisy Chain project in Stockton-on-Tees is an example of a project where families set up their own respite services in order to provide the flexibility and expertise they require. Some of the NAS's schools have been able to use the specialist facilities and skills they have to successfully offer autism-specific respite care at weekends and during holidays.

The Brent and Barnet Short Break Scheme is managed by the National Autistic Society and funded by Brent and Barnet Social Services, through the Carer's Grant. It provides short breaks free of charge either in the home or in the community for children and adults with an ASD. The breaks are provided by a Project Worker, or two if required, for three hours at a time, over twelve weeks

²⁵ Tarleton et al (2002) *Better for the break?* Shared Care Network: York

²⁶ Gray, P (2006) National Audit of Support, Services and Provision for Children with Low Incidence Needs, DFES Research Report 729, DfES: London

mainly in the evenings and weekends. The scheme reaches 70-80 families per year across the two boroughs and currently employs ten staff. Both the staff and the client group reflect the ethnic diversity of the two boroughs, and the services are able to be flexible to meet specific family or cultural needs. It costs £50,000 a year per borough to provide such a service, and the aim is that by providing respite at an early stage fewer families reach crisis point, or break down. This has an impact on carers' health, family, siblings, and enables the person with autism to access community activities and develop areas of interest and skills with the support of a trained professional in their own home.

- Training in ASD should be provided for providers of respite services to enable them to meet the needs of families of children with autism.

Voluntary sector provision is often restricted by short-term funding contracts, including the need to continually seek ongoing funding sources after start-up and meet different funders' requirements, and local authority provision is subject to resource tensions between health and social services departments. Therefore, an identified funding stream needs to be established for this vital form of support. The NAS would like to see statutory guidance on access and entitlement to short break services.

- Funding streams should be streamlined and cover longer periods of time to allow projects to become fully established.
- There should be a new entitlement to short breaks for families of disabled children along with statutory guidance on access.

Another model of good practice which is now being replicated in other parts of the country is the Greater Manchester Consortium to develop local services for people with autism. This innovative project brings together ten social services departments from across Greater Manchester. The consortium funds and steers the National Autistic Society's Family Services Development Project for the region, which supports the strategic development of local services for people with autism and Asperger syndrome. Autism Services Development Groups have been set up by the Consortium in each of the ten local areas, comprising parents of people with autism and key staff in local services, including health, education and social services and voluntary sectors. The groups are working strategically together to develop and improve local services. They link with each other across the region through the consortium. The NAS Family Services Development Project also acts as the region's central referral point for people with autism and their families and has developed resources including a Parent Resource Pack and Parent Resource Network to meet their needs. There are also parent/carer groups, focussing on autism, in each local area. This project is particularly unusual in that it provides both a regional strategic perspective and local support for families.

Direct payments

Direct payments are a particularly useful form of support for some families living with ASD. A difficulty can be in finding workers who have adequate understanding of ASD. To resolve this, in West Lancashire a database is being developed of personal assistants with experience of ASD to provide appropriate services. Because of a lack of trained workers the NAS is looking to partner with the local authority to provide indepth training on ASD to develop the pool of people available.

Information sharing

A welcome example of a step forward in this area at national level is the creation of a separate category for autism spectrum disorders in the Pupil Level Annual Schools Census (PLASC), enabling the number of children in school with a primary diagnosis of ASD to be recorded from January 2004.

Good practice in the tracking and planning of services is the Irish National Intellectual Disability Database established in 1995 to provide comprehensive information for decision-making in relation to planning, funding and management of services for people with a learning disability. Consistency in categories and methodology enables data to be analysed at a local, regional and national level. Reports calculate the number of people requiring service change between every four years, in for example, education, employment or residential care.

The evaluation of the information management proposed in the Every Child Matters Green Paper provided an opportunity to develop existing systems which has yet to be taken up. A discreet category for autistic spectrum disorder needs to be part of this process. Six local authorities in the northeast have set up the Daslⁿe database, which has been running since 2003. The database of children with ASD in the region aims to provide accurate and comprehensive data to facilitate service planning and research into ASD. Plans are underway in other parts of the country to develop similar databases to ensure that data is effectively shared, and families do not fall through the net.

Telford and Wrekin was one of the trailblazers for Every Child Matters, and focused on information sharing and assessment. Through the effective sharing of information across the area, it was very quickly identified that there were gaps in provision for 16 to 18 year olds with Asperger syndrome. As a result awareness was raised among professionals and the NAS provided training for relevant staff across health, social services and education, and to enable them to work more effectively with people with Asperger syndrome. Services for people with autism are now specifically mentioned within Telford's commissioning strategy.

The National Autism Plan for Children recommends that each local area should set up an ASD co-ordinating group, whose responsibilities include strategic

planning, audit and evaluation of autism services. Chorley and South Ribble PCT is currently working with partners to map services for children with ASD and related social and communication disorders to provide effective information in order to commission services through out the area.

- Local authorities should record the numbers of children with autism in their area and should map services for people with autism to ensure that services meet local needs and enable families to access services.