

The All-Party Parliamentary Group on Autism (APPGA) was established in February 2000 to raise parliamentary awareness of autism and campaign for changes to government policy. Members of the APPGA come from all the major political parties, working together to promote the interests of people with autism and their families.

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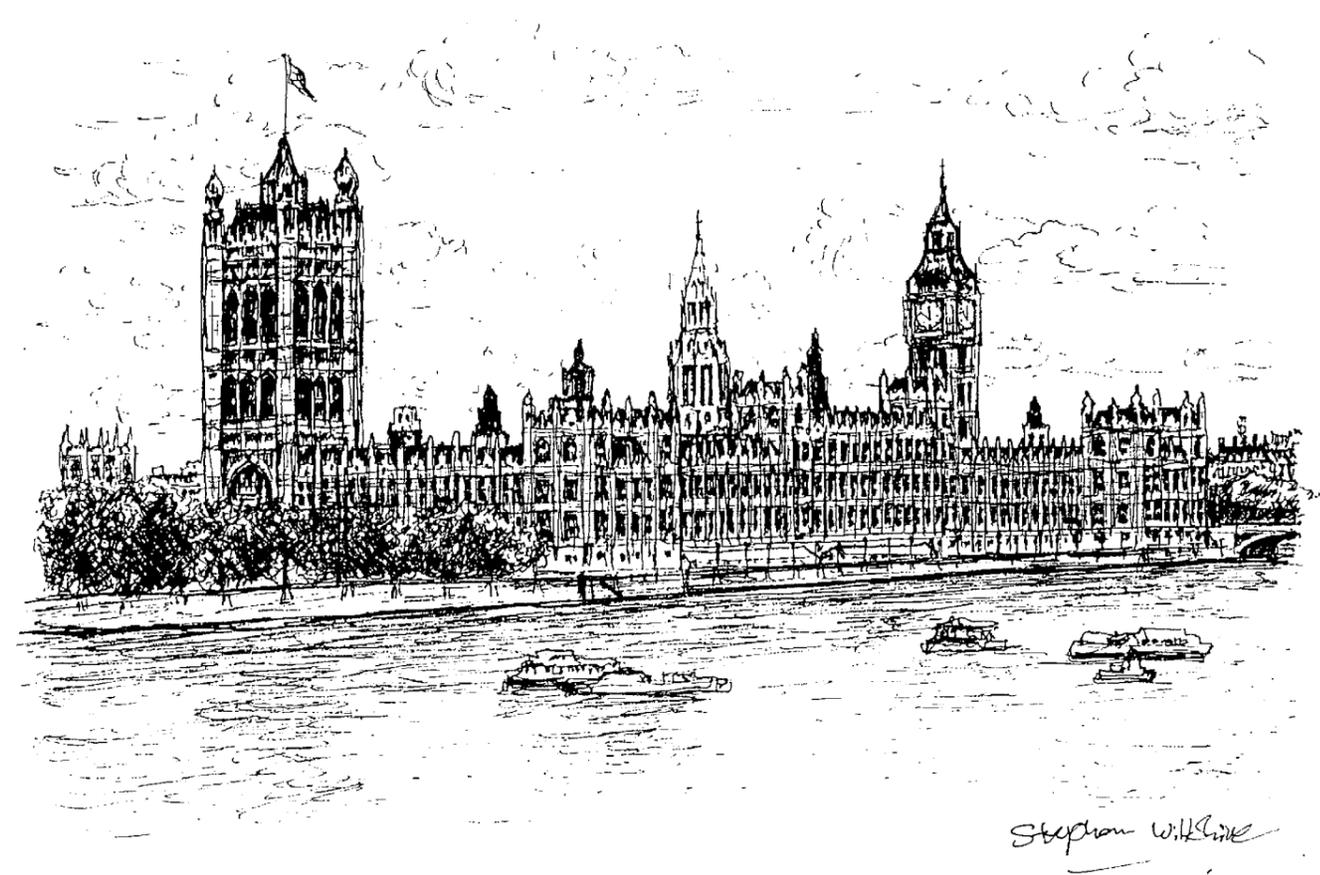
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The All-Party Parliamentary Group on Autism



Transition to adulthood

Inquiry into transition to adulthood for young people with autism

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June 2009

Acknowledgements

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Introduction

“People with ASD don’t cope well with new people and change.”

Professional

For all young people, the transition from childhood to adulthood involves consolidating identity, achieving independence, establishing adult relationships, and finding meaningful occupation. For disabled young people, this transition is made more difficult by concerns about if and how their support needs will be met.

The difficulties of transition from childhood to adulthood for disabled young people have been well documented and the Government has responded to this by launching the Transition Support Programme¹. The reason for the All-Party Parliamentary Group for Autism (APPGA) Inquiry, the findings of which are reported here, is the uniquely challenging nature of transition for those with autism². Transition involves many changes and those with autism find change intrinsically difficult. This is compounded by the current failure of public services to understand, or adequately respond to, this very particular difficulty.

The APPGA selected transition as the topic for this Inquiry because its manifesto progress report, *Half way there?*, highlighted transition as a key focus area for policy makers, arguing that, while there had been much progress in specific areas, the transition process itself and the link between services often fails individuals on the ground. Furthermore, the 2007 report into the economic consequences of autism by Martin Knapp and

others³ estimated that autism costs the UK economy £28 billion a year. The APPGA believes that getting transition right is one of the key strategies required to reduce that figure.

If young people on the autism spectrum are to reach their potential, it is vital that we have high, yet realistic expectations for them. With varying levels of support, many can live full and independent lives. However, currently only 15% of adults with autism are in full-time paid employment⁴. The failure to adequately support young people on the autism spectrum has repercussions for the individual, their families and for public expenditure.

Adequate planning is the bedrock of a good transition. However, only 53% of young people with autism who have statements of special educational needs (SEN) were issued with transition plans during the course of their education, falling to just 34% of students in mainstream schools⁵. The input of adult social services is crucial to the viability of the transition plan and yet adult social services were only involved in planning in 17% of cases.

Such poor transition creates a chasm between the aspirations of young people with autism and the reality experienced by many adults on the autism spectrum. The failures of the system become internalised as the failures of the young people themselves, as they find themselves unemployed and living at home or, in the worst-case scenarios, in prison, or experiencing significant mental health problems. For want of a good transition, a good adulthood for people with autism is being lost.

This Inquiry sought evidence from a range of stakeholders across England, including parents, people with autism and professionals. This report outlines the key findings of the Inquiry and makes recommendations based on the experiences and evidence from all those who took part.

Inquiry methodology

The Inquiry was launched on 9 December 2008 at a reception hosted by Phil Hope MP, Minister for Care Services. The deadline for submission of written evidence was 13 February 2009.

Overall, 229 submissions were received that can be broken down into the following groups:

177⁶ parents/carers

10 parents/carers who are also professionals

29 professionals

8 people with autism

1 family/friend

1 spouse

3 respondents who did not disclose their situation.

The responses from professionals included a group response from Newham’s Asperger Service, which, in turn, included the views of a number of parents, individuals with Asperger syndrome and social workers in that Service. However, the submission did not reveal the exact numbers of people involved.

In March 2009, two oral evidence sessions were held. On 2 March, both young people with autism and parents of those with autism attended to give evidence. On 11 March, professionals attended to give evidence. A full list of those giving both written and oral evidence is included in Appendix 2.

Findings

What young people and their families want

Those submitting evidence were clear about the elements required for transition to work well. They argued that planning should be person-centred, and that it needed to start early because of the difficulty that those on the autism spectrum have with new situations, requiring additional time to prepare for change.

They argued that planning should be carried out in partnership with parents because of their clear knowledge of their child’s needs. However, they were clear that, in addition, a young person should have access to independent advocacy to ensure that their voice was heard and supported in their own transition planning.

They wanted those carrying out the planning to have realistic expectations for individual young people, and wanted them to understand the difficulties that young people with autism might find, particularly in maintaining employment, regardless of their intellectual capacity. However, they also wanted those involved in the transition planning process to have expectations for those on the spectrum and not consign them to

¹ See Appendix for more details on the Transition Support Programme.

² In this document, the term ‘autism’ has been used to include all autism spectrum disorders, including Asperger syndrome.

³ Martin Knapp, Renée Romeo and Jennifer Beecham, *The Economic Costs of Autism*, Foundation for People with Learning Disabilities, November 2007.

⁴ Reid, B., *Moving on up? Negotiating the transition to adulthood for young people with autism*, National Autistic Society, 2007.

⁵ *Make School Make Sense*, The National Autistic Society, 2006.

⁶ This included 119 parents who submitted views via TreeHouse, the autism education charity.

unemployment, simply because so many on the autism spectrum are not in employment. Neither did they want them to fall back on stereotypes (e.g. by assuming that people with autism should work with computers), but to really look at their individual skills and what they could achieve.

They wanted all professionals involved in transition to have an understanding of autism, what it means for a young person and how it may impact on their experience of the transition process, and their need for support. They argued that one person should be identified who would then see the young person with autism through the transition process, be the point of contact for the young person and their family, and liaise with all the other agencies involved. They were very clear that good transition relied on good inter-agency working.

They wanted both parents and young people to have adequate information on what options are open to them. However, they argued that it was vital that young people with autism also had the opportunity to try out different options, so that they could make a concrete choice based on some kind of experience, rather than on abstract concepts with which they might struggle.

They argued that funding for post-19 support should be based on assessed need. They were also really clear that the process of transition should look at areas occurring throughout life, where the person with autism may require support – marriage, having children, divorce, retirement, redundancy – all of which may pose challenges for the person with autism.

Good practice

Some of the parents and professionals who responded had experienced just such ideal transitions:

“The children’s team contacted the transition team on my son’s 14th birthday. A transition team worker arranged a house visit immediately, to discuss possibilities for adult placements. An information pack on local facilities was left for us to consult. An adult learning disability social worker was chosen within two months, to match our son, and visited the house to agree the places chosen.

The social worker spent the day on two boarding school annual reviews, between 14 and 18 (15+ and 16+), seeing our son alone for one hour each time, to get the feel [of him] and become familiar to him. He also drove down with us, to get to know us (95 miles). When our son was suddenly excluded from school at 17, the social worker visited our house, again spending time alone with him, and we rushed forward the plans for transition. Our son was relaxed, as he knew and trusted the guy. He transferred to a local horticultural training scheme within four months.”

Parent/carer

Additionally, this ‘ideal’ transition demonstrates that, because of the behavioural difficulties which can accompany autism, good transition needs to be able to absorb the unexpected undramatically and, where it does so, good outcomes are possible. Difficulties do not have to have an irredeemably negative impact.

It was also clear from evidence submitted that some local authorities were very committed to improving transition processes for young people.

Surrey’s transition process

Surrey County Council has set up a transition team, based in adult services, who link in from age 16 (with plans to do this from age 14). Person-centred planning is in place in some specialist children’s services and an autism-specific handbook about adult services has been developed, as well as an Options for the Future booklet for young people.

An autism commissioning process has been set up to develop local individualised accommodation and support services for young people in transition. The process responds to individual requirements for accommodation and support, as young people come through transition. It picks up young people identified as having autism by the Children with Disability Register (CWDR), as well as those known to specialist schools and children’s services in the county. Those identified are discussed at transition meetings.

People on the autism spectrum who are not on the CWDR but may need a service are highlighted by Connexions at transition meetings. Connexions are in touch with all young people going through transition in the county. There is a possibility of young people being missed if they are not on the CWDR, and are ‘out of county’ at residential school, as Connexions may not be in touch with them locally. These young people are generally flagged up by children’s social work teams.

The process has identified that the number of adults with autism known to statutory learning disability services will double over a twelve year period. Although this is at least partly to do with a lack of recognition of autism in adult services, Surrey believes that it offers an opportunity to get things right for this group.

Consultation has also been carried out with young people with autism and their carers that identified a clear requirement for change in services. Between the consultation and the demographic data, Surrey has been able to make the case for resourcing changes and development of new services.

Surrey’s transition process is a multi-agency one. Once those eligible for a service have been identified, the aim is to ensure the right professionals are engaged, and that actions and responsibilities are agreed in a timely way. Surrey has a lead manager for adults on the autism spectrum who takes part in this process to ensure that actions involving young people on the autism spectrum are prioritised appropriately.

Unfortunately, for the majority of the people who submitted evidence, the transition processes they had experienced had been less than ideal and, as clear as they were about the elements vital to good transition, there was equal clarity about the problems that follow on from poor transition. What the evidence to the Inquiry reinforces is that, while

poor practice around transition planning may be problematic for any young person, getting it wrong for a young person on the autism spectrum can have catastrophic consequences that may be irredeemable because of their inherent difficulty with new situations:

“What is often unrealised is the degree to which anticipation can destabilise someone with ASD. For example ... an adolescent ... developed a psychosis because of their level of emotional arousal (a combination of excitement and anxiety) at the prospect of a holiday. Thereafter, those caring for him were careful not to tell him of any plan until a short time before and until he was familiar with what it entailed. This meant that, when he was due to stay somewhere, he would go for a series of brief, social visits until he was familiar with the people and the place before being told that he would be staying there.”

Royal College of Psychiatrists

Key findings

Submissions to the inquiry highlighted the following themes as central to effective transition:

- effective and timely planning
- realistic yet stretching expectations
- effective joint working across services
- understanding of autism amongst professionals
- accessible information for young people and their families
- appropriate funding.

Planning

For young people and their families approaching transition, a plethora of legislation and statutory guidance leads them to believe that education, health, social services and the Connexions Service will coalesce around a plan designed to meet their needs once they leave school.

It states that the planning will start when the young person is in Year 9, generally aged 13 or 14, at the annual review of the young person’s statement of SEN.

Those who submitted evidence wrote at length about the impact that insufficient planning had on their clients or relatives. As indicated by the Royal College of Psychiatrists, a recurrent theme was the mental health problems which developed as a result. It was clear from the evidence that all too often decisions about a young person’s next placement were not decided until just before the end of their schooling or, in the worst cases, until after they had finished school or college:

“It is impossible to enable a successful transition if placements are not decided until the last minute (or even later!), handover of information becomes incredibly difficult and the young person – who by the nature of autism finds transitioning difficult, ends up being in the next placement with no real time to prepare for this huge change.”

Priors Court, independent specialist school

In fact, due to the lack of provision, such decisions often need to be made well in advance because the waiting time for some places could be years, rather than months. In addition, where young people are moving to independent supported placements, from the point at which funding is agreed and accommodation found, there is usually a minimum period of six months required to recruit, vet and train staff – a time-span often unacknowledged at the start of the process. Where decisions are not made sufficiently far in advance, parents report young people being left at home without any provision, while they wait for a place to become available.

This was an issue across the spectrum. Where young people were going off independently to college or university, parents identified the importance of preparing them for the change to a less structured curriculum and living away from home, but indicated that, without a statement of SEN, such help was seldom available:

“We were told that our son was not eligible for help because Asperger syndrome is a neurological condition and not a learning disability.”

Parent/carer

“My daughter has Asperger syndrome and no statement and really we have been left to support her ourselves as she has always been considered too able for support, but she has suffered with significant mental health problems and still does to a certain extent but we have paid for all the support she has had.”

Parent/carer

Often, those submitting evidence argued that, because it did not start early enough, transition planning failed to be a process, and became an event. Where this happened, there was not time to put young people at the centre:

““We have had situations where a core assessment has been written by a social worker based upon the minutes of an annual review (without ever meeting the young person) which has later been distributed to the parents who were not even aware that it had been written!”

Priors Court

Clearly, where young people have very limited communication abilities and time and effort is required to try and elicit their views, a failure to do so excludes them from any opportunity of taking part in planning for their own future.

Many parents who contributed highlighted the importance of an effective partnership with parents, for a group of young people who often struggle with communication and for whom parental involvement is likely to play a key role in moving forward. However, they had not always experienced such partnership:

“I have not seen my son’s transition plan”

Parent/carer

For some of those submitting evidence, it seemed that a badly-executed transition plan would be better than none. For young people on the spectrum but without learning difficulties, many suggested that there was a widespread lack of recognition of needs past school age, resulting in a failure to plan to meet those needs:

“Despite considerable social difficulties at school (which resulted in school phobia), my daughter was refused a statement. Because of this, she had no access to trained support (or any support). She was, and still is, not eligible for a raft of services which those with a statement or learning difficulty have access to as their right, like independent living skills training, anger management, money management and budgeting, supported housing, specialist housing options, supported employment, Direct Payments, social care, befriending schemes, specialist social activities and more.”

Parent/carer

Expectations and support

There were two main concerns from contributors around expectations. One concern was that, for more able young people, there was insufficient understanding about the level of support they would still require, in order to successfully transfer onto a higher education course, or find and retain employment.

A number of parents felt that a lack of understanding from professionals resulted in young people being set up to fail and that they were assessed for future placements on too narrow a basis – for example, taking into account only their intellectual ability, and failing to understand the impact that being on the autism spectrum might have on an individual's ability to manage the other elements that make up a higher education placement.

One of the witnesses, a young woman with autism, spoke about the importance of the workplace support which she had received:

“As much as I have developed my skills, I will always need support from other people.”

Person with autism

Sarah's evidence highlighted some excellent practice around employment support. Her employer, BT, had a reasonable adjustment scheme in place for disabled people, and a lot of thought was put into job design and ensuring that managers understood the impact of the disability.

However, Sarah also spoke about the difficulty caused by the lack of autism-specific training and support for potential employees looking for work. This point was backed up by other contributors. One parent, whose son was working as a freelance illustrator, wrote about the level of support necessary to enable her son to work which meant that she herself was not in a position to work:

“We found the Disability Advisers at the Jobcentre very willing, but unable to offer the level of personalised help that was needed. Emphasis on college and training was not helpful in our case, because our son has agoraphobia and rarely goes out..., and help in the home was not offered, apart from somebody from Working Links, who visited infrequently and was supportive but unable to offer much in the way of help...”

If I had not been in a position to offer this level of support, there is no way he would have received it from anyone else... We have found that there are a lot of people out there, both government and independent, who are there to give advice, but far fewer who can actually offer work opportunities, or help the person to actually be able to do their work.”

Parent/carer

The other concern about expectations was that they were too low, that the current poor statistics around employment led to unemployment becoming a self-fulfilling prophecy. The lack of expectation and support meant that opportunities were not sufficiently explored or supported.

The concerns about support, however, were much broader than unemployment. Contributors highlighted the importance of those planning and providing support having well-rounded expectations which encompassed all those areas that most of us take for granted as necessary for quality of life, but where those on the autism spectrum may need additional support – for example, independent living skills, relationship counselling, and leisure activities. Such support was seen as critical to the maintenance of good mental health and for fostering independence from carers.

Contributors wanted young people to have access to a consistent source of support to take them through from school to either continuing education or employment, until they have built up new relationships with the next professional:

“Having someone outside the family who knows the young adult and knows the system – what help can be accessed, additional grants, etc – and the same person following through over the years. Working with a stranger is near impossible for him; he has to have time to learn to trust a new person. Someone we can contact to ask questions we as parents have – he has Connexions at school, but we have no contact with them and they don't really know him, judging by the careers advice they gave, ranging from playing cricket as a professional (dyspraxia) to joining the armed police!!!”

Parent/professional

Joint working across services

It was also suggested that a key element of successful transition was having a person who was responsible for making it work:

“Just one key worker who is responsible for liaison with all the other agencies. What can go wrong is when no one is responsible and referrals from agency to agency are not acted upon”

Parent/carer

Again and again, those submitting evidence spoke about the nightmare of a process in which many agencies were involved, but no agency was taking responsibility. Parents talked about people not ‘doing what they say they are going to’:

“My personal experience was that imminent judicial review (stopped at the 11th hour as a meeting was miraculously arranged!) was the only way to ‘encourage’ the people who should have planned my son's transition but consistently failed to do so?”

Parent/carer

Every Child Matters made it clear that ‘by 2008, local authorities are required to have in place arrangements that produce integrated working at all levels, from planning through to delivery, with a focus on improving outcomes’. Despite such clear expectations from central government, it is apparent from evidence to this Inquiry that there is a real lack of effective interagency working. Such a lack around transition can lead to devastating consequences for young people with autism. In the worst cases, young people are ending up in prison, or with very severe mental health issues. If they do, there is very little prospect of any help:

“Adult mental health teams will usually be prepared to take a referral for an individual with a recognised adult mental health disorder, such as early onset psychosis, depression, anxiety disorder, obsessive compulsive disorder etc, but have no specific services for individuals with ASD/Asperger syndrome.”

Royal College of Psychiatrists

Adult mental health teams are often unwilling, or unable, to undertake a diagnostic assessment of someone who does not have a clear mental health condition but is simply not coping with their college/university course or employment.

Whilst access to services seems to be a particular problem for more able young people, evidence suggested that there was difficulty across the spectrum in getting access to mental health services.

Professional training and development

Another very strong theme was the need for further training and development in autism for professionals involved in transition. This theme interrelates strongly with the two previous sections:

“We have people in control of young people’s destinations through life who do not truly understand ASD.”

Parent/carer

There was a feeling that those professionals involved in transition needed to have a real grasp of autism and understand that young people might need not only advice on employment options but also access to specialist training in independent living, social and friendship skills, and workplace culture. They might very well be able to do the tasks of a job but might struggle with the accompanying social interaction and need support in place for it to work long-term.

The importance of Connexions advisers having an understanding of the autism spectrum was mentioned repeatedly. One of the witnesses, suggested that one of the difficulties that sometimes led to inadequate support from a Connexions adviser was their workload. Connexions personal advisers have a caseload of around 150 young people, together with insufficient training in autism spectrum disorders:

“A few years ago, you had specialist training, but now you only have generic personal adviser, and there is not a lot of incentive for people to train.”

Professional

Having staff with a real understanding of autism and an ability to explain the transition process to young people was seen as being absolutely

key to enabling young people to take an active part in planning for their future. Staff involved in the transitions process need to be aware of autism-specific strategies for communication, to understand that open-ended questioning might not be helpful for some young people with autism, and that young people with autism may struggle with abstract concepts. For young people with communication difficulties, contributors noted the importance of an understanding of strategies, such as video diaries and social stories.

As well as wanting those involved in carrying out the transition support to have a strong understanding of and training in autism, contributors felt very strongly that unless those responsible for transition planning also had such an understanding there was no hope of things improving. Many people who submitted written evidence suggested that those responsible for transition planning needed training so that they had an appreciation of the consequences to the individual with autism, their family and wider society of getting transition wrong.

Provision of information

A number of people, often parents, cited the importance of provision of information so that young people and their parents were fully aware of the options available to them:

“I have no idea what our options are and what realistically can be achieved.”

Parent/carer

The provision of information to young people themselves was also seen as important to their effective involvement in transition planning. Clearly, if young people are going to have the opportunity to contribute to their transition planning in an informed way, it is vital that services have sufficient resources to enable staff to become familiar with a young person’s communication style and to implement strategies that maximise the amount of information they can comprehend. When contributors talked about information in this context, they meant it in its widest sense – for instance, ‘physically showing them the options’:

“A blank slate is problematic. Informed choice has to be based on experience as it’s hard to imagine something you have not experienced.”

Professional/friend

A number of parents identified the importance of institutions involved in the young person’s transition being able to offer flexibility in terms of how the transfer was managed:

“Being allowed to visit places without other children around. Being able to attend college one day a week for the two years prior to college attendance.”

Parent/carer

With university attendance, a special visit could be made to meet key people and written plans, including a timetable, a campus map and general information, prepared. Contingency plans for family backup and a flexible approach to different students and their needs are important. Advance and contingency planning to try and prevent problems were identified as having a much higher likelihood of success than trying to salvage a placement, once it had broken down.

Funding

Respondents identified a number of issues related to funding. One was that for some parents having fought to get a particular type or level of provision for their children during the years of compulsory schooling, they felt it was unacceptable to have to go through the same process because the funding provider had changed (Part of this issue may be addressed by transfer of responsibility from the Learning and Skills Council (LSC) to the local authority).

There was also a plea that transition should be about the needs of the young person first and funding second, within the context of a realistic understanding of funding levels:

“Many local authorities seem to come to transition meetings with a ‘fee level’ which can be used for the young person in question. This seems to bear no relation to the young person’s needs and we have had situations where the needs as written in the core assessment could not be covered with the costs given as the cap by social services. This leads to the transition time becoming a ‘battle’ between social services costs and parents/ professionals desire for the needs of the young person to be met.”

Priors Court

One parent pointed out that this kind of battle can lead to parents taking a more obdurate stance than they might if they felt there was a real dialogue or partnership over what could be done to meet their child’s needs.

A number of contributors spoke about the way in which currently funding mitigates against person-centred planning:

“Currently, the LSC fully funds specialist college provision and there is often a perverse incentive for local authorities to encourage placements because it effectively delays the point at which they have to fully fund adult social care. This may result in young people who had their needs met very effectively in maintained day special schools seeking residential placements at post-16 and post-19. In many cases, this may be a suitable and appropriate placement but, for many, it is driven by a lack of reasonable alternatives.”

MacIntyre⁷

Another issue is related to LSC funding and two groups of young adults with autism who need support but are not eligible for funding.

The first group are young adults who have finally received a diagnosis of autism post-25, after struggling with school, college and employment. At this point, they are too old to qualify for LSC funding for the specialist college placement they may require to help them develop the social and work skills they need to cope.

The second group are young people whose intellectual ability has enabled them to gain admission to university but for whom the structure and support has been insufficient. These young people fail to get through their first year and return home. However, their term in higher education disqualifies them for LSC funding for specialist further education.

A further point related to funding was the difficulty caused by different threshold levels for adult services that can lead to young people being excluded from services:

“Being told at every turn that my son does not meet the team criteria.”

Parent/carer

This was mentioned as a particular problem for mental health services and, in general, as an obstacle to young people getting the support they need in transition. Other contributors pointed to the difficulties caused by inconsistencies in the remit:

“Age cut offs, criteria and terminology used between different local authorities and between agencies within borough boundaries.”

Kingwood, autism charity

Generally, thresholds are high when resources are limited and demand is high. What underlies these quotes is a basic dearth of provision for adults with autism:

“They can only be supported if the services are there for them!”

Parent/carer

This is backed up by evidence submitted by the National Autistic Society from their *I Exist* report⁸ which found that:

- nearly two thirds (63%) of adults with autism do not have enough support to meet their needs
- 61% of adults with autism rely on their family financially and 40% live with their parents
- 60% of parents believed that a lack of support has led to higher support needs later on
- At least one in three adults with autism are experiencing mental health difficulties due to a lack of support.

The best of transition processes are worthless, if the fundamental problem is that there is nothing to transition to.

Conclusion

It is clear from the evidence submitted to this Inquiry that for many people on the autism spectrum, transition is not working. It is not working in the narrow sense of a smooth handover between child and adult services. In the wider sense, it is not working – and much further from working – in that those with autism are not being provided with the additional support that they need in order to lead full and fulfilled adult lives.

Contributors clearly felt that there was a significant cost to getting transition wrong, both for individuals and for society:

“Professionals, such as psychologists working in the ASD field who act as expert witnesses in the courts, are very familiar with the interface between the penal system and young people on the spectrum.”

British Psychological Society

“Inappropriate planning means more autistic people not being able to access work or living independently, thus more benefits having to be paid out. More mental health damage equals more medical intervention equals more costs to the NHS budget in medication and possible hospitalisation. Not to mention the impact on parents/carers, leading to financial hardship depression, anxiety, family breakdown etc.”

Parent/carer

Such submissions are supported by research evidence. Research from 2000⁹ found that less than a quarter of able individuals on the autism spectrum had gone on to find placements in some form of employment.

Mental ill health was highlighted as an all too common consequence of a badly-handled transition process:

“People with ASD and learning difficulties have a much higher rate of psychiatric complications than the general population and have difficulty coping with change. Life events or sudden changes (eg due to a lack of planning) can lead to catastrophic reactions which can be very difficult to reverse, especially if the behaviour becomes entrenched over a period of time. Therefore the amount of work and cost involved in pre-empting the problems and addressing potential future difficulties early on is greatly reduced, compared to trying to react to a negative situation once it has already happened.”

Professional

For those submitting evidence, there was a high level of concern about the impact of a lack of transition planning and support on higher-functioning young people. The British Psychological Society pointed out in their evidence that such a view is supported by research indicating that there is a particularly high incidence of mental health issues among the more able autism spectrum population¹⁰.

There was also a concern that higher-functioning young people are at a greater disadvantage because they are less likely to have had adequate support earlier on in their lives:

⁷ MacIntyre is a national charity that provides learning, support and care for more than 900 children and adults with learning disabilities, at more than 120 services across the UK.

⁸ Rosenblatt, M., *I Exist: the Message from Adults with Autism in England*, National Autistic Society, 2008.

⁹ Howlin 2000

¹⁰ Simonoff, E., Pickles, A., Charman, T., Chandler, S., and Baird, G. (2008). Psychiatric disorders: Prevalence, comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47, 921-929.

“Not having a statement means that young people will struggle more in adulthood because they did not get adequate support early on.”

Person with autism

Evidence submitted by Newham’s Asperger’s Service¹¹ perhaps best sums up these concerns:

“Approximately 60% of our service users have experienced additional mental health problems, 30% self-harm, 30% have attempted suicide, 28% have histories of being hospitalised for mental health problems; 15% have been in the prison system, and a further 15% have been cautioned by the police.”

Newham’s Asperger’s Service

There have however been a number of developments in the field of transition, perhaps the most significant being the Transition Support Programme with its research into transition for young people with autism. There is good practice out there and the Transition Support Programme is a welcome Government initiative that aims to spread what are currently small pockets of good practice more widely.

That said, we have barely begun to scratch the surface of the work that needs to be done if all those with autism are to be given sufficient support to lead fulfilled adult lives. We hope that this report and its recommendations will lay down a marker in the sand, in terms of recognising the need to address this wider aim. A successful transition from child to adult services is the very least we can do and, as those submitting evidence to this Inquiry have insisted, we need to have much greater expectations for what adults with autism can achieve.

¹¹ Newham Asperger’s Service was set up to coordinate the delivery of services for adults with Asperger Syndrome or High Functioning Autism. The service aims to:

- provide easier access to assessment;
- provide individual assessments to those who meet the criteria to determine the impact of AS/ HFA;
- signpost to provider agencies, services and advice;
- provide a specialist service to support the most complex needs of some individuals.

What needs to change?

Recommendations for Government

- Guidance should require Directors of Children’s Services to maintain a database of the numbers of children with autism in their area and share this information with Adult Services.
- Guidance should require that Directors of Children’s Services and Directors of Adult Social Services co-operate to review and plan services for young people with autism on a regular basis, including those children with complex needs in out-of-authority placements.
- The Government should extend the duty on local authorities to ensure that a multi-agency person-centred transition plan is developed for each pupil with autism who receives support at School Action Plus from the age of 14, in addition to those with a statement of SEN.
- The disabled children’s services national indicator (NI54) should be extended and young people’s views gathered in a survey so that there is a specific focus on transition against which local areas can be measured. Any future review of the local government performance framework should address the needs of disabled young people during transition to adulthood.
- The Government’s learning disability employment strategy should address the needs of young adults with autism including Asperger syndrome, in line with Public Service Agreement 16.

- The Government should ensure that all children with autism have opportunities to undertake meaningful work experience in Year 10.
- The Government must ensure that disability support advisors at further education colleges and at universities have autism training.
- The Department for Work and Pensions should ensure that Connexions provide information to all young people with autism on Employment Support Allowance and Disability Living Allowance.
- JobCentre Plus should ensure that all transition plans include young people’s employment goals and outline the work support programmes available to them.

Recommendations for Local Authorities and their partners

- Local authorities should meet their statutory duties relating to transition for young people with autism.
- All transition plans should be person-centred and include an assessment of the young person’s social skills and identify training needs in this area.
- Local authorities should ensure there is local access to social skills training for young people with autism as identified during transition.
- Connexions should monitor outcomes for all young people with autism. This information should be used in the planning of future services and support.
- Local authorities should ensure that Connexions services support all young people with autism up to the age of 24.

- Local authorities should ensure that Connexions personal advisors receive training in autism.
- Local authorities should ensure that all professionals who support young people with autism through transition have basic training in autism and are able to communicate with individuals effectively.
- Local authorities should ensure that all young people with autism who require a transition plan are allocated a transition key worker trained in autism to oversee the process and ensure the views of the young person and their family are central to the process.
- Young people with autism should be involved in decisions about their future. Where necessary, appropriate support should be put in place to enable them to communicate their views.
- Families should be included in planning for their son or daughter’s future, and be provided with appropriate and timely information to enable them to do so as an equal partner.
- PCTs should put in place protocols for transferring clinical mental health care for those young people with autism in Child and Adolescent Mental Health Services. Where individuals do not fulfil referral criteria for adult mental health teams, measures must be put in place to ensure that those individuals can receive support elsewhere, particularly through the transition process. Commissioners must be informed of gaps in services in these instances.

Appendix 1

Overview of existing guidelines and Government action

The *Disabled Person's Act 1986* requires local education authorities (now children's services departments) to seek information from social services as to whether a young person with a statement of SEN is disabled and so might need services from the local authority when they leave school. Under the *Children Act 1989* and the *NHS and Community Care Act 1990*, social services are expected to arrange multi-disciplinary assessments and establish plans which may include further education for children in need, including those with significant special needs. Social services should also ensure that a social worker attends the Year 9 (13/14 years) annual review meeting and contributes to the formation of the transition plan.

The SEN Code of Practice

The SEN Code of Practice sets out what should happen during the transition process. It states that the annual review of a child's statement of SEN which happens in Year 9 (age approximately 14 years) should involve the agencies that may play a major role in the young person's life during the post-school years and that it must involve the Connexions service. Health authorities should be aware of the process. Social services must be invited so that any parallel assessments under the *Disabled Persons (Services, Consultation and Representations) Act 1986*; the *NHS and*

Community Care Act 1990; and the *Chronically Sick and Disabled Persons Act 1970* can contribute to and draw information from the review process.

The SEN Toolkit

Additionally, the SEN Toolkit, which provides more detailed guidance on transition for professionals, makes it clear that health professionals involved in the management and care of the young person should provide advice towards transition plans in writing and should, where appropriate, attend the annual review meeting in Year 9. They should advise on the services that are likely to be required and should discuss arrangements for transfer to adult health care services with the young person, their parents and their GP.

The SEN Toolkit also states that social workers should identify and attend the Year 9 reviews of young people who are eligible for assessment under the *Disabled Persons (Services, Consultation and Representation) Act 1986*. It suggests that for children living away from home, the Year 9 review will be a particularly important opportunity to begin to identify adult placements, relevant networks and possible supported living placements.

The most recent statutory requirements and policies that affect transition are found in:

- Valuing people now¹²
- Every child matters¹³ and the subsequent *Children Act 2004*;

- the National Service Framework (NSF) for children, young people and
- maternity services 2004 – Standard 8¹⁴ focuses on children with disabilities and complex needs, and chapter 7 of Standard 8 has a specific focus on transition.
- Improving the life chances of disabled people;¹⁵ and
- Transitions: young adults with complex needs¹⁶.
- the Best practice guidance on the role of the director of adult social services (DASS)¹⁷ makes it clear that the DASS should be responsible for the arrangements to support the transition of service users between different service providers, and between children's and adults' services and sets out a number of expectations for those in the role.

In addition to such general guidance, the Department for Children, Schools and Families' website www.teachernet.gov.uk includes autism-specific good practice guidance and the section on transition identifies some key points for improving transition.

The Transition Support Programme

Aiming High for Disabled Children (AHDC), launched in May 2007, is the Government's transformation programme for disabled children's services in England. The programme rightly identified that more work was needed to improve and co-ordinate services for disabled young people in transition to adult life. To address this,

the Government announced the Transition Support Programme¹⁸, which aims to raise the standards of transition in all local areas. After short breaks, transition is the next most heavily-funded stream of work under the Aiming High programme.

The Transition Support Programme consists of two main elements:

- the national transition support team, which will coordinate the work with local authorities, PCTs and regional advisers and existing experts
- support for change at local level, through a combination of direct grants and regional adviser activity.

In December 2008, the Government announced that every local authority area will receive £10,000 to assess their current support for transition, including asking for the views of local young people and their families, and completing a self-assessment questionnaire. Thirteen local authorities are receiving an additional £37,500 to extend their practice in the following areas:

- engagement with disabled young people and also their families
- personalisation
- joint assessment processes in children's and adult services
- education, employment and training options at 16+
- strategic partnership working.

¹¹ Newham Asperger's Service was set up to coordinate the delivery of services for adults with Asperger Syndrome or High Functioning Autism. The service aims to:

- provide easier access to assessment;
- provide individual assessments to those who meet the criteria to determine the impact of AS/ HFA;
- signpost to provider agencies, services and advice;
- provide a specialist service to support the most complex needs of some individuals.

¹² *Valuing people now: A new three year strategy for people with learning disabilities*, Department of Health 2009.

¹³ *Every child matters*, The Stationary Office, September 2003.

¹⁴ *Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services*, Department of Health, October 2004.

¹⁵ *Improving the life chances of disabled people*, Cabinet Office, January 2005.

¹⁶ *Transitions: young adults with complex needs, A Social Exclusion Unit Final Report*, ODPM, November 2005.

¹⁷ *Best practice guidance on the role of the director of adult social services*, Department of Health 2005.

¹⁸ www.transitionssupportprogramme.org.uk

From April 2009, funding of £10,000 and support will be provided to every local area to help build multi-agency engagement into planning processes. The funding will also enable greater engagement with young people about access to recreation facilities, training and work, as well as completion of an annual questionnaire. Three differentiated bands of support are available to local areas:

- 1 direct grant and support from the national transition team to develop best practice and drive change in other areas
- 2 regional adviser days, to help promote use of networks and best practice, from the National Strategies and the Child Health and Maternity Partnerships (formerly CSIP)
- 3 regional adviser support days, to move practice on from minimum standards, from the National Strategies and the Child Health and Maternity Partnerships.

The self-assessment questionnaire will be used to determine the level of support required for each local area.

Appendix 2

Oral and written evidence was received from the following individuals and organizations:

| | | | |
|------------------------------------|--------------------|------------------------|--|
| Pat Smith | Sarifa Patel | Jeremy Marchesi | Tom Booth |
| Paul Rowen | Rozina Hussain | Jamie Stewart | John Savage |
| Mary Langan | Lyndsay King | Susan Burns | Dr Helen Pearce |
| Anna Peterman | Helen Harris | Ann Griffin | Ruth Martin |
| David Shamash | Jacqueline Alty | David Sexton | Elaine Butler |
| Carolann Jackson | Mrs Meg Bott | Nickki Smit | Mrs E Dacks |
| Helen Shaw | L E Simpson | Jan Percival | Karen Varga |
| Mrs Debra de la-Nougerede Sinclair | Rachel O'Brien | Alexander Percival | Rachel Carli |
| Colin L. Hughes | Sally Hopkins | Charlotte Elgar | David Wood |
| Adriel Yap | Carolann Jackson | Anonymous | Carol Marquer |
| Jody Johnson | Marieanne Hickman | Nicola Winson | Cian Binchy |
| Pauline Cole | Anna Kennedy | Claire Pedley | Alison Reade |
| Mrs Zena Maciver | Eunice O'Connell | Judith Kerem | Grace Hsieh |
| Christina Faruki | Ruth Over | Alison Mitchell | Dennis Gissing |
| Hilarie Gedroyc | Audrey Martin | Lynne Pullin | Sarah Hewitt |
| Liz Keeley | Michelle Mould | Alison Upfold | Foundation for People with Learning Disabilities |
| Anna Lansley | Jan Millward | Anonymous | Kingwood via Lady Hornby |
| Yvonne Wilson | Rosalind Brewer | Dawn Bendall | Thomas Moore and Sandy Thomas, Surrey County Council |
| Nevin Penny | Sara Heath | Lyndah | Thomas Moore and Sandy Thomas, Surrey County Council |
| Jenny Fookes | N Brownless | Julie Corbett | British Psychological Society |
| Lynn Bonser | Nicola Martin | Angela Thompson | Newham Asperger's Service |
| Dr Melanie Smith | David Pinniger | Marilyn Kramer | Royal College of Psychiatrists |
| Richard Lawrence | Susan Kerry | Marc Bush | TreeHouse |
| Rosalyn Lord | Kathy Smith | K. Lloyd | New Philanthropy Capital |
| Heather Squires | Julie Birch | Andrea McCombie-Parker | MacIntyre |
| Claire Nerval | Jean Eastabrook | Anonymous | Tony Brown, Autism Diagnostic Research Centre of Southampton |
| Caroline Morrell | Raymond Dragonetti | Karen Adams | |
| Rhiannon Thomas | Debra Hudson | Hazel Fricker | |
| Catharine Morris | Fern Clive | Donna Booth | |
| | Barbara Rendell | | |

Notes: