



# A Life in the Community...

Supporting adults with autism  
and other developmental disorders  
whose needs are challenging

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When the large institutions for people with learning disabilities were being closed, there was much optimism about the future for the former residents. Despite the doubts of some workers in the field, the general view was that placement in a small house in the community was all that was needed to ensure the disappearance of the challenging behaviour shown by some when they lived in the institutions. Reality proved to be different. Many of those with challenging behaviour did not settle down in their new homes and some were moved from one home to another, each change adding to their confusion and distress.

The complexities of the organisation of community care, involving a multiplicity of agencies, led to, as the editors of this report point out, uncertainties and disputes about who had responsibility for the 'hard to place' people. This report tackles the issues raised by these experiences. It discusses all aspects, including individual care, staff recruitment and development, issues of health care, and the need for joint working among all the different bodies involved.

A large proportion of people with challenging behaviour arising from untypical patterns of development have conditions within or on the borderlines of the autistic spectrum. Out of the many important points emphasised by this report, one stands out as crucial. This is the need for carers and others to try to see the world from the point of view of the person concerned, which is particularly difficult in the case of autism. It takes knowledge, experience and imaginative empathy to understand why someone with little comprehension of language always becomes aggressive when given instructions he cannot understand. Or why someone who cannot habituate to loud noises smashes the television set when a programme about motor racing is shown.

However difficult it is to achieve this understanding, the effort is worthwhile. It is the key to the provision of an environment that gives the person concerned a quality of life that is suited to their individual needs, which is the most effective way of solving the problem of challenging behaviour. The brief histories given in this report make this point with clarity.

The report is a blueprint for the future pattern of service provision for a group of people whose problems and needs have too often been misunderstood.

Dr Lorna Wing

## Background

This report is about those individuals whose needs are the most challenging and complex, the majority of whom have an autistic spectrum disorder or learning disability. Characteristically they will have difficulties communicating and interacting socially. They will also have a restricted range of interests and activities and a tendency to resist changes in routine. Some will have very repetitive, obsessive and compulsive behaviours. Although a comparatively small group of people, they, nevertheless, require a very substantial amount of support. Their problems are often longstanding and first evident in the school age years. The characteristics of this group of people pose special challenges for services with regard to communicating with them, discerning their needs, fostering their social integration and providing them with life opportunities and support.

During the year 2000, discussions amongst Trustees of the Kingwood Trust revealed the worrying extent and complexity of the problems that organisations providing social care for this hard to place group of people were experiencing. These difficulties were not just within the providing organisations, but related to the whole system of health and social care. There were uncertainties and disputes between health and social care funders about where the responsibility for these 'hard to place' people lay, issues about the availability of specialist support, problems within services with staffing levels and the availability of appropriate skills. More generally, poor communication and joint working between the many agencies involved, families and the people themselves exacerbated the problem.

It was against this background that the Trust decided it would seek funding for a project that would bring together a multi-disciplinary group of professionals with parents to explore the issues, identify good practice, and develop a set of recommendations that will contribute to improvements across agencies and at all levels.

Having successfully secured funding from The Three Guineas Trust, a steering group was formed from key organisations, including the Kingwood Trust, the Autism Research Centre at the University of Cambridge, The National Autistic Society and The National Development Team for People with Learning Disabilities (*see appendix 1 for details*).

This group gathered information about services, issues and good practice, and planned and ran a professional workshop, which was attended by 35 delegates in February 2001 (*see appendix 2 for the list of participants*). As well as keynote presentations from leaders in the field, the two-day workshop used small groups to work on the issues identified, and to develop ideas and recommendations for good practice, which were then shared and discussed amongst the wider group. Facilitators from each small group wrote up the findings from their discussions.

This report is the outcome of this process. It draws on the information from case studies collated by the steering group, data from a questionnaire completed by workshop participants, the key note addresses and the material produced by the small groups from the workshop.

## Values and policy

Underlying the discussions at the workshop were a number of fundamental principles about the values underpinning services, and the policy context within England. It is important that these are made clear.

Historically people with learning disabilities, whatever their needs, have been excluded from the mainstream of ordinary life, and often placed in segregated settings in large groups, with very little or no say in what happened in their lives. Over the last thirty years the two important ideological movements of ‘normalisation’ and ‘empowerment’ through civil rights have gradually changed the way services perceive and respond to people with learning disabilities. There is now a recognition that people with learning disabilities both want and have the right to the same things in life as everyone else – a home of their own, relationships, opportunities to grow and develop, being treated with dignity and respect, and control over their own lives.

This is finally reflected in Government policy with the publication of the White Paper, *Valuing People*, which sets out how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities.

In 1993, Professor Jim Mansell wrote in his report *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs*:

*“People with challenging behaviour have the same needs as everyone else, in addition to special needs for help to overcome the problems their behaviour presents. They do not surrender their needs for personal relationships, for growth and development or for anything else because they have challenging behaviour.”*

The Mansell Report went on to emphasise that the quality of the mainstream services and the ordinary learning disability services affected the number of people with challenging behaviour, so the better these services, the less reliance on very specialist services. This is as true today as it was then. The new White Paper makes it clear that the same values that inform generic services for people with learning disabilities should inform the way services support people who have complex needs and are ‘difficult to place’. This means a policy of ‘zero rejection’ – no-one is excluded from the approach, however complex their needs. Well informed, imaginative and sensitive thinking about how individuals can be best supported is essential.

The Mansell Report illustrated the challenges of supporting people with more complex needs. Sadly many of these challenges remain. Moreover, since the report many changes have occurred in the way services are planned, resourced, organised and run. For this reason, it seemed important that renewed consideration was given to the specific issues of supporting people with autistic spectrum disorders, or who otherwise are ‘hard to place’, in the context of these values and the new White Paper.

**Key points:** *The same human rights and values apply to this group of people as all others and services for them should be operating in the context of the same social policies, particularly as enshrined in the Government's strategy for people with learning disabilities, Valuing People.*

## Key themes

Themes that were important in supporting people with autistic spectrum disorders, or who were otherwise 'hard to place', were identified through the examination of case material and through the questionnaire completed by workshop participants.

These themes fell into two broad categories: the importance of individuals having a choice about where and how they live and the implication for services.

Key themes in the first category were:

- ◆ Finding out enough about people to make effective individual plans: this included issues about assessment and person centred planning
- ◆ Preparing individuals for changes at key stages of transition in life and at other times
- ◆ Identifying options for living that provided the environments and living arrangements best suited to someone's needs and wishes
- ◆ Extending opportunities for a fulfilling life through work, lifelong learning and a range of social and leisure activities.

In the second category, key themes included:

- ◆ Getting the funding and commissioning right; this has to be flexible, involved, local and accountable
- ◆ Providing good quality social care through a workforce appropriately trained, managed and supported
- ◆ Ensuring access to specialist support and other services from health and other agencies
- ◆ The need for better integration of services with more effective joint working and partnership
- ◆ Developing standards and quality assurance processes that safeguard people's lives.

## Person centred planning

The Government White Paper recognises the importance of a person centred approach to planning for individuals. This means taking an approach that is not service led, and which is not in itself an assessment process. Person centred planning is a family of approaches aimed at helping an individual and those people most important to them to figure out what kind of life that person wants, what kind of support that might mean, what kind of community change might be involved, and what kind of progress can be made by whom and over what time. It focuses on the positive – what people like, what skills or talents they have and what things they would like to do or learn. Done properly, it helps restore the power to the person to determine for themselves what their life is about, and how it is led.

*Monica had been very unhappy in her group home, which was quite a distance from her parents and friends. Although she had lived there for two years, she would get upset and cry if people described it as her home. Sometimes she would take out her frustrations on those around her. Her key worker helped Monica look at who was important to her and what her goals and aspirations were. Her circle of friends and family were then invited to a planning day which allowed Monica to state what she wanted and what help she would like to achieve her aims. A list of actions was identified along with realistic timescales. A major outcome of the process was Monica moving into a new home with two other people she liked and wanted to live with. Everyone now comments on how positive and confident Monica is, in comparison to the withdrawn and sad person she had once been.*

Person centred planning is just as relevant for people with autistic spectrum disorders, but poses some very particular challenges for services. The person at the centre may find it very difficult to be involved – there may be problems with routine, excessive anger, rage attacks, and insecurity in the environment. Communication difficulties may make it very difficult to elicit information or determine wishes and needs. This means that special attention has to be paid to:

- ◆ Collating all the information that is already known about the person, for example, from previous assessments and individual planning processes
- ◆ Careful recording of observations to identify what people like, enjoy and respond to, as well as what causes them stress
- ◆ Identifying shortfalls in understanding about aspects of the person or their behaviour, which may require further specialist assessment or advice
- ◆ Careful thought about who is important to the person, and who should be involved. Sometimes unlikely people have relationships with the person which can shed a different light on them or their situation – it might be a cleaner or a particular relative
- ◆ Thinking hard and imaginatively about communication – about what works, where it works and how it works; it may entail special techniques or technologies and may involve any of the senses



- ◆ Planning ways of fostering growth and development and increasing life opportunities: these need to be sensitive to the wishes and needs of the individual and have to be appropriately paced
- ◆ Enabling people to be creative and flexible in their thinking about the person and what might help or interest them
- ◆ Being clear about who is going to be responsible for what, and that all the right supports are in place
- ◆ Reviewing progress regularly, to identify both progress and problems, so that issues can be tackled quickly and lessons learned.

Most of all, evidence from good practice indicates that the most essential ingredient for successful person centred planning is commitment from all concerned. Organisations that do well for people, especially those with more complex needs, are person centred through and through – ‘It’s like the writing in Blackpool rock!’

Person centred planning is a very organic and fluid process which not only needs commitment but also needs to be linked in to the more formal decision making processes within organisations. This requires robust communication and stability in the official processes of clinical assessment and care management that form the interface between the person, their own ‘planning circle’ and ‘the system’. It requires the specialist staff who undertake assessments or manage care to recognise the importance of person centred approaches and find positive ways to contribute their knowledge and understanding.

***Key points:** Absolute commitment to person centred approaches to the planning and delivery of services and supports for individual people are essential for good practice. Because of the very specific needs of individuals within this group, the best results come from person centred planning around particular individuals, where ways are sought to actively involve both them and other key people in the process. Specialist assessment and care management processes should positively contribute to and link with individual person centred planning.*

## Preparation for change and transition

Everybody’s life involves change at some points. Some of these changes are at times of key life transitions that happen to us all – going to school, moving from primary to secondary school, leaving school and joining the adult world. Later there is a further transition phase from adult life into old age. These changes are largely determined by age and developmental needs. And then there are other transitions that differ for every individual – moving home, school or job.

For everyone change can be stressful, even if desirable. For people with autistic spectrum disorders who are hard to place, change can be especially stressful, even when planned and needed. Changes in the environment or to established routines often lead to disturbed behaviours, which, without careful planning and preparation, make a potentially positive move into a bad experience.

*Mark was detained at Broadmoor as a restricted patient following a second offence of arson. After eight years, he was referred for a move on to a specialist unit for adults with Asperger's Syndrome. In order to maximise the chances of the transition from closed hospital to community unit working, a clear programme of visits by Mark to his new home was established, followed by the move. The whole move was planned as a structured programme agreed in advance with both Mark and his family. After two years, and having settled, Mark moved on again in a planned and structured way to a semi-independent house, where he now lives successfully.*

The problems for this group of people often begin quite early in childhood. Right from the start there needs to be a lot of planning, and the planning needs to be based on good information about individuals who are due to enter a transition phase. For example, the school, educational psychology or further education services need to make information available about any children who are due to move from school to further education, or from further education into adult provision. With the right information, effective transition planning can then take place between the key professionals from the service from which the person is moving, and from the new services to which they are going. Specialist advisers and care managers should facilitate this process and plans will be the more robust for the active involvement of the people themselves and their family carers.

Once plans are in place, a lot of detailed work then needs to be put into the preparation for the change, so as to minimise the stress and the possibility of negative behaviour developing that could jeopardise the plans. This will require in-depth knowledge of the person – knowing their stress triggers and the most effective ways of managing uncertainty. Timing can be crucial, and there will need to be appropriate flexible contingency plans to take account of the stress and its consequences. In this context it is important to consider the provider organisation's capabilities and its own need for support.

When making preparations for placement changes for this group of people, continuity in the structure of the environment provided for individuals is often very important, for example, in the type of communication support required. Any new care organisation should be able to provide an appropriate range of communication supports. Change of placement could be facilitated by gradually introducing individuals into the new placement. This could be further facilitated by ensuring that staff from the new provider unit spend time with the individual in their familiar and established provision, getting to know them and establishing a relationship with them, as well as assisting with the transition process.

Inevitably during the key transition phases there are often significant changes for people not just in terms of their personal circumstances, but also in the organisations and agencies responsible for the provision of care and support. For example, during the transition from school to adult provision, there is a transfer of responsibility from the local education authority to social services, as well as from paediatric care to adult health services. As a consequence, there is a need for a lot of inter-agency work to clarify who is responsible for what, particularly the funding arrangements. Sadly, disputes about funding are one of the main causes of difficulty at times of transition.

In the workshop, examples of good practice were characterised by a key dedicated person, such as the Connexions Personal Adviser, with detailed knowledge and understanding of the individual, carefully planning the transition. However, transition planning and management were often vulnerable to changes of such key workers. This points towards a need for the development of a multi-disciplinary group for planning transitions. The group would be responsible for overseeing complex changes for individuals. It would be led by social services and involve representatives from healthcare and education, with the lead coming from the home county or borough.

The group would be responsible for liaising with potential social care providers and other key organisations – housing, employment, and further education. It would collect information about individuals coming up to age and developmental transitions, for example at 14+ years, and would also be responsible for undertaking or commissioning the assessments necessary for formulating appropriate plans for transition. The transition plans would need to be person centred and involve the family and past and future providers, and would need to ensure continuity in the structure of the environment.

The group would focus on the management of the most complex transitions. All this would require a clear and responsive referral process.

**Key points:** *Special attention should be paid to planning around individuals at times of change and transition in their lives, as these times can be very threatening for this group of people. Consideration should be given to the creation of specialist multi disciplinary groups for planning transition. For this group of people, careful and sensitive preparation for change can make a large difference to the outcome.*

## Housing and support

Two of the most significant factors identified in examples where placements had broken down were problems in the environment and incompatibility with other residents.

For many people with autistic spectrum disorders, the environment is of particular significance. It seems extraordinary how often services, when faced with someone who does not like noise or a lot of other people, and for whom lack of tolerance is an issue, then places them in a ‘special unit’ full of noisy people who do not like a lot of other people themselves. Others do not like cramped conditions, or dark corridors, or too much clutter.

It is well known that people with autistic spectrum disorders like structure, rhythm and routine in their lives, and yet too often they are placed in environments where these issues are not addressed. Or if they are, there are too many conflicting demands from others for them to be adhered to effectively.

Very few people with learning disabilities, let alone those with more complex needs, choose with whom they live. In many parts of the country, people resettled from hospital

over the past twenty years are now being resettled again because they do not get on with each other and want to 'move on'. It could be argued that this issue is even more important for people with autistic spectrum disorders. Their tolerance of others is often low, and if they do not like their compatriots, serious problems can ensue. Practice examples revealed physical assault as a key issue in the breakdown of placements.

*Michael, a 35 year old man placed in a small group home was very unhappy and disturbed. He was frequently head butting staff and behaving aggressively. He said he wanted to return to his parent's home, which was not possible. Staff and his care manager facilitated meetings with Michael and his parents separately and together to look at options: what Michael would like, what he would not like, what would be possible. The idea of moving back to his hometown, near his parents but living independently with support, was pursued and seemed to meet his wishes and needs. A house was acquired through shared ownership and Michael was able to participate in the recruitment of staff who would be supporting him. Incidents of challenging behaviour reduced from 2-3 per week to virtually none.*

It is clear from the experiences of many services, that the person centred planning process needs to take particular account of both environmental issues and compatibility issues that are relevant to that person (remembering they are likely to be different for others). It is essential to know someone very well if there is a chance of getting the environment and who someone lives with right. There is also strong evidence to suggest that using supported living as the approach rather than traditional placements in residential care homes or nursing homes is more likely to increase the chances of a successful placement.

Supported living means each individual choosing a place to live (in a community) that most people might like, with people they choose (and no-one else if that is their choice), with the support they need, under their control, from people who are committed to them. This would enable the issue of the environment to be looked at individually. Compatibility is also at the heart of it. It does not preclude the possibility of 24 hour a day support.

There are a number of examples of supported living working well in practice for people who are seen as 'hard to place'. Although it moves more of the cost in to the benefit system (through use of transitional housing benefit or the Independent Living Fund), and works out cheaper for many, for a few with very high support needs it can work out more expensive than traditional services.

However, given the hidden costs of repeated placement breakdown, and the very expensive alternatives in special hospital units or even prisons, in the long term it could still be the most cost-effective option. More research is required to examine the benefits of supported living and the comparable costs.

People with autistic spectrum disorders are those most in need of unique and bespoke service designs when it comes to where they live. A real challenge is to apply these

principles to individuals with the more severe disabilities and complex needs, whilst ensuring that life opportunities are enhanced and social inclusion promoted.

**Key points:** *Supported living is especially relevant in considering a person's 'placement options' as it is more likely to ensure that both the right environment is created for a person's needs, and that they live with compatible people.*

### Opportunities for a fulfilling life

The wider environment can also be very challenging for someone with an autistic spectrum disorder. It is easy to talk about the benefits of 'being in the community', the increased chances of participating in it, and forming relationships with people who are not staff, but for some this can be daunting. Often the environment of the community seems out of control – noise, congestion, people, moving vehicles, the effects of extreme weather – these things can seem threatening. Sometimes the community is not very accepting – it can seem unfriendly, rejecting or even abusive.

Hence the importance of knowing the person – knowing their idiosyncrasies, likes and dislikes, and the things that trigger stress or anxiety. And the importance of knowing the community. Community for the solitary train enthusiast is very different to the hurly-burly community of the football fan. Life for young people in a quiet rural area is very different to the clubland culture found in many inner cities. Working alone can be very different to the intense teamwork required in some jobs.

*Mary had lived many years in a long stay hospital. She was one of the last to leave because she was seen as having very challenging behaviour and was felt to be generally unco-operative. Mary had little communication, was blind and deaf, and used a wheelchair. A local supported employment agency worked hard with her to find out what she liked doing, and eventually found her a job one day a week in a branch of a well known retailer that sells soaps, creams, oils etc. They discovered that Mary had a great sense of smell and were able to train her to fill the shelves from stock using this sense. The effects of this valued work led to a positive change in her behaviours, and introduced Mary to a new range of people and experiences.*

With many services being reactive and crisis driven, little attention is given to what being in the community means for someone. The skills required to understand and engage with the community are different to those of caring for someone's personal needs, and these skills are often lacking, or are not used. To make social inclusion a reality for people requires not just commitment from the key organisations, but also clear vision about the values underpinning the service, and good understanding about the meaning of community participation.

This is sometimes referred to as ‘community bridge building’. It means:

- ◆ Work on community mapping or inventories so that the resources are recognised
- ◆ Using ordinary mainstream community based amenities and facilities
- ◆ Negotiation and liaison with these facilities to ensure they are accessible and supportive
- ◆ Pursuing more informal community participation through local groups, clubs, associations and leisure activities
- ◆ Providing reliable information to people, their families and the community about what is available and what is involved.

These things are of particular importance in the fields of employment and further education or lifelong learning. Few people with learning disabilities, and even fewer with autistic spectrum disorders, have the opportunity to work, or to develop their skills and interests. To enable them to be included, it is vital that employers, employment services, colleges and those working for the new Learning and Skills Councils are made aware of the issues, and are actively engaged in problem solving, resourcing and otherwise responding.

Encouragingly, a number of successful supported employment programmes do seem to be emerging. For example, the NAS supported employment service, PROSPECTS, has successfully placed and maintained a large number of adults with autism in open employment since its inception in 1995.

Although community bridge building provides important, enhanced life opportunities, there may be a continuing need for some individuals also to have access to parallel, more individualised and tailored structured activities.

***Key points:*** *Social inclusion is just as important for this group of people as others, but may have some very specific meanings and implications for individuals. Specialist advice and support may be needed to help people make use of opportunities for employment, lifelong learning and leisure activities.*

## Commissioning

Although the strict division between ‘purchasing’ and ‘providing’ no longer exists, the overall function of commissioning services is still crucial. By commissioning we mean setting strategic direction, determining service requirements, developing service specifications, procuring and allocating resources and monitoring service outcomes. Commissioning operates at two levels – one strategic and the other for individual people through the care management system. Without effective commissioning at both levels, there will be no leadership to services, no coherence or focus in provision, and there will be a risk of inappropriate responses to the special needs of particular people or groups. As a result, there will be no quality outcomes in service delivery, particularly for people with autistic spectrum disorders and others who are hard to place.

*A County Commissioning Authority had pooled the budgets from health and social services to allow for a single purchasing structure for people with learning disabilities. To support this structure multi-disciplinary teams have been created which brought together health professionals and care managers. This has streamlined their referral and assessment process considerably and allows for a rapid response in a crisis situation. They feel this multi disciplinary approach gives more time and specialist consideration to people whose needs are complex.*

The primary role of commissioning in this context could be defined as finding a fit between the needs of individuals (as defined through assessment, care management and person centred planning processes), the environment (already identified as a key to successful placements for this group of people), and the organisations and structures that provide services. Successful commissioning for ‘hard to place’ adults will involve:

- ◆ Developing services in partnership with providers – moving away from the culture of competitive tendering towards one of identifying preferred providers and working jointly on service specifications and design
- ◆ Investing in local specialist provision, and reducing reliance on expensive ‘out of area’ placements that fragment social networks, and reduce the chances of community participation
- ◆ Top level agreement between health and social services about the needs of people with complex needs, the ways they will be supported, and the funding and other elements that will determine how services are provided.

A major challenge for commissioners in this field is gaining the specialist knowledge required to commission services for this small group of people with specific individual needs. Indeed, it has taken some commissioners considerable time to develop any expertise in the overall field of learning disability, let alone in the highly specialised issues for this group. This problem is likely to grow where the commissioning of services for people with learning disabilities is being moved to Primary Care Trusts (PCTs). One method that could be considered to overcome this problem would be some form of collaborative commissioning arrangement that could provide a small team of specialist commissioners with the right expertise to work with specialist providers to develop services for individuals in their own localities.

Robust and specialised commissioning arrangements would make sure that:

- ◆ The right assessment and planning processes were in place
- ◆ The right people were involved at the right time in the assessment and planning processes
- ◆ Specialist help was available to others involved in the planning process
- ◆ Strong partnerships were forged between the main agencies, defining roles and responsibilities
- ◆ Services were developed at a local level in collaboration with specialist providers
- ◆ Effective mechanisms were put in place for reviewing progress and ensuring positive outcomes for people
- ◆ There was an effective interface with the care management and other important organisational processes
- ◆ A process was in place to increase local learning and knowledge, and reduce reliance on specialist services (as emphasised in the Mansell Report).

***Key points:** Commissioners need to be aware of the issues in relation to services for this group of people. There is a case for considering specialist commissioning teams, possibly on a regional basis, to inform both strategic commissioners and local commissioning through care management. Commissioners need to work in close partnership with providers, to help inform and develop services and support specific to this group.*

### The provision of social care: an effective workforce

There is no doubt that the key to the effective provision of support to people who are 'hard to place' is the quality and availability of appropriate staffing. Time and time again examples of poor practice point to the problems of the lack of staff continuity, the lack of staff with specialist knowledge and skills, high sickness and absence rates, poor rates of pay and lack of career development opportunities.

Some of these problems are true of the social care sector generally. The impact of high employment rates in the South East and other areas, the low rates of pay, the lack of training opportunities in line with good practice are all issues facing the sector. They are of course exaggerated in situations where the expectations of staff are higher – as is the case with supporting people who are hard to place. Failure to address the particular issues of staff stress, abuse from service users, and the increased need for supervision and support can add to an already difficult situation.

Some of these are long term problems with the employment infrastructure but there are many examples of good practice and new initiatives that can make a difference.



In the field of recruitment there are some services that seem to fare better than others. Some of the reasons for this can be identified:

- ◆ The recruitment of staff to meet the needs of a specific individual is often a more successful approach – there is more likely to be a match between knowledge, skills and the needs of the person. Roles are more clearly defined, and job satisfaction potentially greater. This implies the use of supported living and effective person centred planning.
- ◆ The idea of doing something significant, important and different is promoted. This can appeal to people without professional qualifications who might not otherwise consider the work – for example, new graduates and people looking for a career change.
- ◆ Knowing the local employment market – unemployment rates, main competitors and types of work locally – can enable services to target particular groups – young people, people over 55 or those who have retired early.
- ◆ Linking with potential new employment sources – talks at schools and colleges, involving people with learning disabilities in promotional work with students, volunteers.
- ◆ Using new ways to advertise and promote working with people with learning disabilities – videos, web sites, feature articles in local newspapers.

It is not of course just a question of recruitment at any cost. Given the complex needs of people who are ‘hard to place’, the quality of the staff is as important. A balance needs to be struck between quantity and quality. Issues that make a difference qualitatively seem to be:

- ◆ Clarity about the role and responsibilities – generally but especially if it is in relation to supporting a particular individual
- ◆ Developing a ‘safeguards checklist’ – indicators that can help identify an inappropriate appointment: for example people who have left their previous employment suddenly or who are suspended
- ◆ Supporting people with learning disabilities and or their relatives to participate in the appointment of their own staff: the importance of liking somebody, or feeling safe with them, may seem simplistic but it is important to people especially if they find social interaction difficult
- ◆ Offering service managers training in recruitment
- ◆ Making sure that those involved in interviews know the people for whom the staff are to be appointed
- ◆ Providing plenty of information about the job and the service, so that candidates are clear what it is about, and what it involves – videos, opportunities to look round and meet people and induction packs can all help.

Once staff are recruited, there is much that can be done to make sure that they are properly supported, with opportunities to develop new skills and knowledge. Given the specialist nature of supporting people with autistic spectrum disorders, it is essential to have sound staff development policies, with special attention to the particular stresses and skills involved in the work.

Some of the methods that have helped successful services are:

- ◆ Induction training that focuses on the people being supported, together with information on statutory duties.
- ◆ Training that enthuses as well as informs – using and developing skilled and experienced trainers.
- ◆ Ensuring there is some specific training for staff on working with people diagnosed as having an autistic spectrum disorder, as well as training on managing challenging behaviour and in the use of restraint. Awareness of autism and its features will limit misinterpretations of behaviour and reduce misunderstandings.
- ◆ Pro-active policies to prevent high stress and burnout: short term contracts, flexible shift patterns, job swaps and secondments, good support systems and staff development opportunities.
- ◆ Making more use of interactive technologies (for example the world wide web) – a lot can be learned in small amounts of time if structured and made user friendly.
- ◆ Personal development plans for staff – development ‘pathways’ for individual employees that work to peoples’ learning styles and that support career development and improve promotion opportunities.
- ◆ Emphasis on creative problem solving: creating a culture that encourages and supports innovation, reflects on practice and disseminates knowledge.
- ◆ Integrated, portable, accredited, vocational training that links to the new Learning Disability Awards Framework (see *Valuing People*).
- ◆ Staff supervision and support to build an effective team and to ensure that the skills acquired in training are translated into real, practical improvements in care management.

If the goal of social inclusion is as important for this group of people as with others, then staff will need new skills to develop access to the full range of community resources and amenities.

In particular, for people with autistic spectrum disorders, the community itself will need support to become more inclusive. Creating and developing capacity in the community requires networking and other skills not traditionally associated with social care work. These can include mapping community resources, cold calling, marketing and public relations exercises. All this will need to be followed by negotiations to tailor and shape community resources to the needs of the particular individual and efforts to build the community’s confidence. Locating responsibility for this work is important, as is making the time to do it (it can easily lose priority in the face of crisis management). Success often depends on the dedication of staff. Involving people with learning disabilities themselves can be a powerful way to help others understand the issues – for example talking in schools and colleges about citizenship.

*Martin has lived in a small group home run by a local housing association for 18 months having moved there when the local long stay hospital closed. He seemed to settle well, but then the staff of the home said that he should return to hospital, as he clearly did not appreciate ‘what those in the house had to offer’. Martin was smearing*

*faeces, had daily aggressive outbursts and did not take part in house activities. The community team advised that admission to hospital was not appropriate and that they would like to work with staff to try to understand the reasons for Martin's problematic behaviour. Detailed record keeping by the social care staff, and observations by the community team, identified a number of factors that had led to the staff wishing for him to be evicted. These included a limited understanding of the extent and nature of his functional communication impairments, the staff developing negative and ill-informed attributes about his behaviour, a lack of structure, and a very limited use of other means of communication. With excellent support from the senior manager, intensive work with the staff team resulted in a better understanding of his needs, and a more effective support strategy. Martin's behaviour improved and the staff were pleased that he was not forced to leave.*

A service that truly values the people for whom it is working, will also value the staff working for it. A simple but reliable measure of the effectiveness of a social care provider is the extent to which it does this. For example, such awards as 'Investors in People' give an indication of the commitment of the social care organisation to staff and staff development.

**Key points:** *The key to good service provision is an effective workforce. Imaginative approaches are needed to tackle the general problems of recruitment in the social care sector, and the specific issues relating to working with this group of people. Sector wide problems need to be addressed and should not be an excuse for inaction.*

*The quality of staff is as important as the quantity which means that it is important to recruit the right people. All staff need positive opportunities for personal development and training. A major task is to raise awareness of the particular needs of people who are hard to place with staff in provider organisations and mainstream services. New community bridge-building skills will be required to raise awareness in the community and promote social inclusion.*

## Specialist healthcare

Although the goals for people will be primarily social, good health is vital to their achievement, and strong links between the social and health care services are essential. The Government's White Paper, *Valuing People*, sets out the importance of access to good quality health care – both primary and secondary – for all people with learning disabilities. It maps out the role of specialist health services in facilitating access to health care, and in raising the health care professionals' awareness of the needs of these individuals.

Regular health check-ups and routine care is especially important for people with limited communication skills, as physical pain from quite simple things like toothache or the effects of more serious physical illnesses can trigger challenging behaviour.

More specifically, for people with autistic spectrum disorders and learning disabilities there is a high risk of developing other psychiatric or psychological problems, especially anxiety, depression, obsessions, compulsions and sometimes even psychotic illnesses, with delusions and hallucinations. They have a right to evidence based health practice with a sound diagnosis, and informed treatment approaches. It is therefore important that there is access to a good quality specialist health services that can provide the psychiatric and psychological support to individuals, and other service providers.

*Matthew lived for most of his life with his parents. He was diagnosed as having autism during childhood and attended local special schools. He has very limited spoken language but does use some signs. After leaving school Matthew moved away from his family home to a privately run group home for 12 people with challenging behaviour. Over the next few months there were several serious aggressive outbursts. Staff came to dislike him, and were not willing to establish a more predictable environment, or to use other means of communication.*

*A crisis led to an inevitable hospital admission. However, this provided the focus for the development of a better home for Matthew. When in hospital much of his more problematic behaviour was preventable through improvements in communication. There was evidence of some periods of depressed mood, and when 'low' he was much more likely to have an aggressive outburst. His mood fluctuations were treated with carbamazepine (a drug used to treat mood disorders). Matthew moved to a local group home for four people where staff were familiar with the use of various communication strategies, and structured enjoyable day activities were identified for him. He has now lived there successfully for three years with minimal problem behaviours.*

Unfortunately, very few consultants have expertise in the field of learning disability and psychiatry and access to mainstream psychiatric services is often difficult. Moreover, in many parts of the United Kingdom there is also a shortage of clinical psychologists. Many areas are under-resourced and lack the full range of specialist professionals, including community nurses, occupational therapists, speech and language therapists. There is a particular danger that with the increasing emphasis on social care and the changing role of the health service for people with learning disabilities, the specialist health care resources that are needed will be fragmented or lost. They perform vital functions as a 'safety valve' and are part of the continuum of support to which this specific group of people often needs access.

The special needs of this hard to place group mean that access to specialist health services are essential for good quality assessment, treatment and support to other services. They play a crucial role in helping to inform effective person centred planning, and would be essential back up to any specialist commissioning arrangements, specialist transition teams, and local community learning disability teams. It is imperative that service development plans recognise this and identify the skills and resources that will be required in different localities.

- ◆ Effective use of general and specialist health services means good joint working arrangements between social care providers, specialist health care services, mainstream learning disability services and the rest of the health service
- ◆ On-going involvement and early intervention will lead to better outcomes for people than relying on crisis based contact
- ◆ Social care staff can assist healthcare workers by observing and recording details of behaviour consistently and accurately
- ◆ Healthcare specialists should raise awareness and understanding of autism and learning disabilities amongst staff and provide training to staff and family carers
- ◆ Health care services can provide important support during crises by assisting with assessment, advising about management and by providing input from nursing and other professional staff to support care-workers.

**Key points:** *Access to specialist health care support is a very important part of the continuum of care and support for this group of people. It provides an important role supporting other services as well as providing specialised assessments and interventions.*

### Joint working

Social policy has regularly extolled the virtues of joint working over the past twenty years, and yet the reality is often very different with few effective partnerships. Moreover, every time policies, services, professions and organisations change, how they work together has to be renegotiated.

With the current major changes in the organisation of healthcare services, especially mental health and related social care, this is especially relevant. Recognition that all people with learning disabilities, including those who are hard to place, have the right to a life of their choosing in the community means a whole range of new stakeholders has to be brought in to the equation. This includes housing associations, the Employment Service, the new Connexions service (formerly the Careers service), the new Learning and Skills Council, leisure service departments in District Councils and Metropolitan Boroughs and so on.

The Government's new strategy for people with learning disabilities, *Valuing People*, recognises this and requires each county or borough to set up a Partnership Board. The Boards need to reflect the diversity of the different people and groups who need to be involved and work together. It is also suggesting that these Boards make use of new powers conferred in the recent Health Act to create new flexibilities in the way services are jointly planned, commissioned and funded, including 'pooled budgets'. It is important that these Boards recognise the issues specific to those individuals with autism and who are hard to place, where the level of joint understanding and problem solving required is perhaps greatest.

However, it is not just at this level that joint working is required. It needs to go on at all levels:

- ◆ Person centred plans need to draw on all those individuals and services important to that person and focus on their needs – not the vested interests of the organisations and agencies involved.
- ◆ Assessments may be necessary from a range of different professionals and specialists but the information gleaned needs to become part of a broader holistic assessment. Best practice suggests that multi-disciplinary working is the best way to achieve this. There are good examples of multi-disciplinary teams that facilitate joint working, and the proposed transition teams (see above) would promote this way of working.
- ◆ The commissioning of all the appropriate services and supports for an individual need to be co-ordinated and coherent – this is the role of care management. It will be easier to achieve where there is strong joint working and more especially a sense of joint responsibility, rather than a culture of ‘buck-passing’ or ‘cost-shunting’.
- ◆ Strategic commissioning needs to ensure effective joint working between agencies and organisations by making imaginative use of the new flexibilities for joint commissioning and pooled budgets. In the case of very specialist areas, such as the commissioning of services for the hard to place, there is a case for creating some kind of inter-agency group to work on the issues jointly at local or regional level.

**Key points:** *Joint working and partnership between all key stakeholders is essential at all levels – from Partnership Boards to personal planning around individuals. Joint working requires trust, shared vision, and shared responsibility, particularly for people who are traditionally hard to place. Partnership Boards should make use of the new flexibilities for joint commissioning to promote joint working.*

### Quality standards and safeguards

There are two key themes that emerge when considering how the quality of a service can be assured, and what safeguards can be put in place to maximise people’s opportunities and safety at the same time. These are firstly that there is a framework of civil rights that protects the legal entitlements of an individual and secondly, that services and the organisations that commission and provide them are driven by the quality of the outcomes they deliver for people.

Until recently, there was not a formal framework that set out peoples’ civil rights in this country. This meant that neither was there any formal policy setting out the rights of people with learning disabilities. However, the way services have been provided and developed, and the way social policy has been framed, has been influenced by the civil rights movement that began in the United States in the 1950s.

These rights became embodied in the social model of disability, with its emphasis on non-discriminatory practice. And there is now a Human Rights Act in the United Kingdom, which ratifies all the rights embodied in the European Charter of Human

Rights. These apply to all people, irrespective of disability or anything else, and give people the basic human rights, for example, to life, to the prohibition of degrading or inhuman treatment, to marry and have a family life, to privacy and personal possessions, and to a home. This now provides a legal framework for the rights of all individuals.

In the Government's new strategy for people with learning disabilities, it is clear that the ultimate test of the quality of a service is now accepted as its efficacy for an individual – whether it achieves the outcome desired by that person. Together with the emphasis on human rights this raises two sets of issues for services and organisations in relation to quality assurance:

- ◆ How can the outcomes in terms of peoples' experience of services be measured? Unless this is known, services will not know whether they are being effective or not. This raises more difficult issues in services for people for whom it is not always clear what a good outcome would be, because they may have difficulty articulating it.
- ◆ What are the processes and services that are most likely to promote the achievement of positive outcomes for people? In particular, what are the 'best' ways of supporting people with autistic spectrum disorders and who are hard to place?

The experience of the past two centuries has finally taught us that the best outcomes for people will differ from individual to individual – that they are needs not service based. So when people do not seem happy, it is not an issue about changing the service model (for example from hospital to hostel then to group home), but of starting with each individual and their needs, and framing the services individually in support of them. This has posed a serious challenge to those both seeking to identify outcomes and to translate them into implications for services.

Although what is right for one person may not be right for another, there are some frameworks that can help in finding out about outcomes. John O'Brien and Connie Lyle developed their 'Five Service Accomplishments'. These highlight the key areas to evaluate in determining the extent to which a service helps a person achieve what they want. The areas include:

- ◆ The extent to which the service helps the person live in a community of their choice
- ◆ The degree to which individuals are treated with dignity and respect
- ◆ The amount of control people have over their own lives
- ◆ The opportunities they have to develop their talents and interests
- ◆ The opportunities they have to make and form relationships, including intimate ones.

More specific frameworks have been developed that identify key measures that people with learning disabilities themselves have defined as being the most important outcomes. Some of these frameworks (see for example the Quality Network) also include processes for helping to elicit the information about outcomes for people, especially from people who may not communicate easily.

There is sufficient experience of good practice now to indicate some of the attributes, processes and approaches of services that achieve good outcomes for people, and more specifically for those with more complex needs:

- ◆ Meaningful consultation with and involvement of people who use services in identifying their own needs and formulating their own plans
- ◆ The promotion of self-advocacy and citizen advocacy for people who find it difficult to speak up for themselves
- ◆ Proper regard for human rights and the specialist support some people will need for them to be truly respected
- ◆ The provision of good quality and accessible information
- ◆ Attention to different means of communication
- ◆ Local commitment to develop support for people who are hard to place that respect important relationships for the person and give them strategies for real control over their lives and their own behaviour (for example using Direct Payments)
- ◆ Access to specialist skills to strengthen local services and support for individuals at specific times
- ◆ Investment in staff development and training
- ◆ Openly balancing risks with duty of care for individuals through good person centred planning (rather than blanket 'risk assessments' or policies that are more about protecting staff or the agency).

For many of these it should be possible to develop sets of indicators that would give some basic information about whether a service is likely to be of good quality. For example in the field of staff training and development this could include the numbers of staff with qualifications, records of courses attended and the amount of resources allocated to training. More generally, indicators of whole services could cover issues of size, recognition from accrediting bodies (e.g. The Autism Services Accreditation Programme), perceptions of local communities and other services. A framework for developing measures of service quality is outlined in appendix 3. Attention to these issues will not guarantee successful outcomes, but will increase the likelihood of their achievement.

**Key points:** *Commissioners should ensure that services are developing in ways likely to promote rights based quality outcomes for this group of people. Commissioners and providers need to ensure there are processes in place that seek to identify outcomes for people, and link the information back into service planning and development. Sets of practice based indicators should be developed that will give commissioners regular insight into which providers are likely to be providing the better quality services.*



People with autistic spectrum disorders, or who are otherwise hard to place, have the same rights to social inclusion and good health care as everyone else. To offer them more choice in terms of where and how they live, services must be committed to a person centred approach that is highly sensitive to the different needs of every individual. Supported living and access to a diverse range of community based services are elements in person centred provision.

Specialist skills and resources are required to support existing commissioning and social care agencies, promote access to community facilities and services and provide specific and timely interventions for some individuals, where appropriate.

It is imperative that these principles and practices are recognised, and implemented. If not, resources will be eroded, specialist expertise and understanding will diminish and a small but nonetheless deserving group of people will lose their right and entitlement to a decent ordinary life in the community.

## Appendix 1

### The steering group

Dr Patrick Bolton (Chair)	Trustee – The Kingwood Trust and Co-Director University of Cambridge Autism Research Centre
Keith Hasted	Co-ordinator – The Kingwood Trust
Dr Tony Holland	University Lecturer University of Cambridge and Autism Research Centre
Joan Maughan	Chief Executive, National Development Team
Mary McGuire	Charities Consultant, Lorien (formerly of The Kingwood Trust)
Richard Mills	Director – Services, The National Autistic Society
Judith North	Chief Executive, The Kingwood Trust
John Northfield	Trustee, The Kingwood Trust
Zadie Orr	Lead Commissioner, Oxfordshire Joint Commissioning
Dr Oliver Russell (observer)	Department of Health

## Appendix 2

### Workshop participants

Helen Aguirre	Lifespan Healthcare NHS Trust, Cambridge
Caryl Anderson	Yarrow Housing
Ann Barwood	Social Services Inspectorate Department of Health
Peter Bates	National Development Team
John Beckett	MacIntyre Care
Lucille Bennett	British Institute of Learning Disability
Dr Tom Berney	Northgate and Prudhoe NHS Trust
Yvonne Cox	Oxfordshire Learning Disability NHS Trust
Barbara Dewar	The National Autistic Society Broomhayes School
Prof. Eric Emerson	Institute for Health Research University of Lancaster
Lisa Flack	The Kingwood Trust
Robert Goodman	National Control and Restraint General Service Association
Keith Hasted	The Kingwood Trust
Dr Tony Holland	Autism Research Centre University of Cambridge
Lady Hornby	The Kingwood Trust
Robert Hubbard	Prior's Court School
David Johnson	Advance Housing
Jane Jones	Somerset Total Communication
Dr Rita Jordan	School of Education University of Birmingham
Nick Keene	Oxfordshire Learning Disability NHS Trust
Tony Leatherbarrow	Renaissance Social Housing Ltd
Jane Livingstone	Association for Residential Care
Joan Maughan	The National Development Team
Brian McGinnis	MENCAP National Centre
Mary McGuire	The Kingwood Trust
Richard Mills	The National Autistic Society
Judith North	The Kingwood Trust
John Northfield	The Kingwood Trust
Zaidie Orr	Joint Commissioning Oxfordshire County Council
Pat Purkis	Parent
Tony Purkis	Parent
Ailsa Russell	Institute Of Psychiatry
Dr Oliver Russell	(observer) Department of Health

## Appendix 3

### Key Areas for Developing Service Quality Indicators

#### Person centred planning

- ◆ Needs, wishes and aspirations of individual and family identified
- ◆ Appropriate, well-planned development programme to enhance life opportunities and social inclusion and to promote supported living and employment
- ◆ Regular review of plans and provision with clear opportunities for the person to influence service provision, for example involvement in staff recruitment, appointment of an advocate for the service user
- ◆ Level of satisfaction expressed by individual and their relatives

#### General characteristics of service organisations

- ◆ Shared philosophy, values, knowledge and understanding (person centred approach)
- ◆ Commitment to service users and service development
- ◆ Well-planned and co-ordinated strategy for developing community based services
- ◆ Evidence of effective joint working and partnerships
- ◆ Experienced and well trained workforce
- ◆ Good information systems
- ◆ Involvement with developing systems for quality assessment and inspection (e.g. the NDT and BILD Quality Network; The Autism Services Accreditation Programme; The Learning Disabilities Award Framework; The Care Standards Commission)

#### Commissioning

- ◆ Funding arrangements
  - Clearly identifiable, properly planned and costed budget based on accurate information and forecasts about service users and their needs
- ◆ Good, effective and well established relationship with education, social and healthcare providers
- ◆ Clear and effective procedures for transition planning and management
- ◆ Mechanisms for accurately and meaningfully measuring and monitoring outcomes and links to other inspection activity

#### Social care provider organisation

- ◆ Relationship with commissioners, healthcare services and community
- ◆ Awards, accreditations and registration (e.g. Investors in People; The Autism Services Accreditation Programme)
- ◆ Monitoring of success and failures (placement breakdowns, staff disciplinary rates)
- ◆ High quality information (service users needs and wishes, staff and organisation performance) and clear mechanisms for reporting and acting on information
- ◆ Staff recruitment and induction programme (involvement of service users and their relatives)
- ◆ Staff qualifications and experience

- ◆ Staff training and development programme
  - Commitment and support (time and financial)
  - Knowledge of Government's recommendations in "Valuing People" and implications for service provision
  - Autism awareness
  - Communication skills
  - Challenging behaviour and restraint
  - Measures for putting skills into practice and sustaining quality
  - Paths and mechanism for promotion and reward
- ◆ Staff support programme (rate of turnover)
  - Mechanisms for preventing isolation and burnout
  - Promotion of peer support
- ◆ Staff-service user ratio
- ◆ Range of services
  - Communication supports and skills
  - Daytime activities
  - Supported employment opportunities
- ◆ Range and flexibility of services and procedures for crisis prevention and response
- ◆ Homes
  - Location and access to community
  - Number and mix of residents
  - Safety (location, glass, radiators)
  - Record keeping (incident reports and rates)
- ◆ Community mapping and bridge building exercises

### **Healthcare services**

- ◆ Primary (for example, routine health checks)
- ◆ Psychiatric and community learning disability teams
  - Staffing and resources (psychiatry, psychology, speech, occupational and physical therapists)
  - On going relationship with service users and providers
  - Approach to crisis prevention and response (support to service user and social care provider)

### **Education**

- ◆ Range of provision and rate of out of county / authority placements
- ◆ Well-developed and tailored learning skills and career development programme
- ◆ School based behaviour support programmes
- ◆ Quality information systems and planning
- ◆ Joint working between schools, health, social services and Connexions with evidence of active involvement in transition planning

## Appendix 4

### References

*The Human Rights Act.* HMSO London 1998.

*The Health Act.* HMSO London 1999.

*Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* (Mansell Report). HMSO London 1993.

*The Principle of Normalisation in Human Services* by Wolf Wolfensberger. NIMR Toronto 1972.

*The Framework for Accomplishment* by John O'Brien and Connie Lyle. Responsive Systems Associates Georgia USA 1977.

*Valuing People.* HMSO London 2001.

## Appendix 5

### Details of the key organisations:

#### **The Kingwood Trust ([www.kingwood.org.uk](http://www.kingwood.org.uk))**

The Kingwood Trust, founded in 1994, is a charity that specialises in the provision of social care of adults with autism spectrum disorders / learning disabilities whose needs are challenging.

#### **The National Development Team for People with Learning Disabilities ([www.ndt.org.uk](http://www.ndt.org.uk))**

The National Development Team is a not for profit Friendly Society committed to working with people with learning disabilities for better services and for opportunities for a fulfilling life in the community.

#### **The National Autistic Society ([www.nas.org.uk](http://www.nas.org.uk))**

The National Autistic Society was established in 1962 and has since grown into the UK's foremost organisation for people with autism spectrum disorders and those who care for them. It spearheads national and international initiatives and provides a strong voice for autism. The organisation works in many areas to help people with autism spectrum disorders live with as much independence as possible.

#### **The Autism Research Centre at the University of Cambridge ([www.psychiatry.cam.ac.uk/arc/](http://www.psychiatry.cam.ac.uk/arc/))**

The ARC is a multidisciplinary research centre that was established at the University of Cambridge in partnership with Lifespan Healthcare Trust, The National Autistic Society and other UK charities. It researches the causes of autism spectrum and related disorders, the psychological and behavioural manifestations and the effectiveness of treatments. It also has a strong role in education, training and service development.

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