

Improving Commissioning Standards in Services for Children and Adults with Autism Spectrum Disorders

Produced by a working group of commissioners and autism-specific service providers in the North West, with the support of The National Autistic Society.

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This discussion paper comes from a working group of commissioners and autism-specific provider organisations in the North West - the first such initiative in the UK. It reflects their commitment to:

- Recognise the complexity of the autism spectrum, particularly in relation to provision of services to people with Asperger's syndrome.
- Stimulate the development of a range of autism-competent services provision, both locally and regionally across the education, health, housing and social care spectrum.
- Have a clear expectation as to the competencies a service should demonstrate.
- Move towards personalised services
- Help children, young people and adults with ASD to gain support to remain within or close to their families and local community
- Develop services that work across the transition between children's and adult services.
- Develop monitoring and quality control mechanisms
- Engage with families and people with autism as the final determinates of both quality and outcomes.

This work stems from two linked initiatives, Partners in Autism (North West) and the Greater Manchester Autism Consortium. The former group comprises autism-specific service providers in the region. It was set up by the National Autistic Society (NAS) to promote strategic planning and development of services and to extend partnership working to that end. In September 2004, it held a workshop with commissioners leading to a set of documents on Autism Commissioning Standards which are drawn together here.

The Autism Consortium, comprising all ten local authorities in Greater Manchester and the NAS, has also identified a confusion and lack of clarity about the use of autism-specific services. Most authorities are also experiencing an increase in demand for specialist placements, many of which are very expensive, and some many miles from the person's home area.

Acknowledgments

This paper draws on consultation with colleagues in the North and on the work of the North West Autism Task Group (2003), NAS Guidance for Inspectors - CSCI (2005), Jones and Jordan (2001) and Robertson and Emerson, Lancaster University, 2006

IMPROVING COMMISSIONING STANDARDS IN SERVICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS (ASD)

The context for commissioning

Achieving the Every Child Matters agenda of co-ordinated front line delivery will require:

- Services to be reconfigured
- Some services to cease and new ones set up
- Resources pooled

Commissioning is seen to be one of the keys to achieving these radical changes. The new reality for Local Authority, Health, and Independent Sector services is decommissioning and re-commissioning. However, this needs to be seen in the context of:

1. Finite (and sometimes diminishing) resources

This can mean that price not quality may be the driving factor. The autism-specific element of the service may then be less well founded and the provider's commitment to high quality services may be undermined.

Limited resources can also lead to a more positive shift in commissioning towards preventative and early intervention services, since this is the most cost effective in the long term for many people with ASD. To achieve this, there often needs to be an invest to save approach which may require resources to be shifted from existing services. However, this strategy does not usually lead to financial benefits in the short term.

2. Relatively limited experience in commissioning

Regional Centres of Excellence are working with partners on a skills framework for commissioning and procurement but until that is in place, there will be:

- varied practice between areas
- few staff with qualifications

- a need for training especially for staff with an education background as commissioning has been less common in education than social care or health

3. Local Authority financial regulations and procurement strategies that focus on cost as the prime criterion

These were originally designed for construction type services rather than the delivery of services to individuals and there are strong inherent tensions in their application to services.

There should be an autism-specific element in commissioning all services for children and young people with ASD and their families,. This is needed not only for working with young people with the most severe needs but also with those with moderate needs, where an appropriate autism specific intervention may make a significant difference to the outcome. For example, for a verbal teenager with Asperger's syndrome it may make the difference between going into or staying out of the criminal justice system.

There are two sorts of commissioning standards to address:

- a) the standards that autistic children and their families should expect from the public bodies that commission services
- b) the standards that providers (whether public, voluntary or private) should be expected to deliver.

Commissioning standards expected from public bodies

1. Agencies should have an effective needs analysis process in place.

This involves:

- an audit of the number of children and young people needing services
- an analysis of outcomes – what is being achieved and the gap between this and what is required.

An analysis of need which is based on good data is vital to planning but currently the data on ASD in each area is still not adequate for effective commissioning. Although data within individual services is improving, effective commissioning at local and regional levels needs to have:

- more accurate data and integration of information between health, education and social care.
- agreement on definitions and prevalence levels especially on how to include children and young people with Asperger's syndrome.
- better transfer of data at individual and group levels during transition from children's to adults' services.

2. Agencies should ensure that young people, their families and key practitioners are fully involved in the commissioning process

This is a vital part of the Every Child Matters agenda and not all commissioners are yet able to do this effectively. It is critical to the needs analysis, service mapping, prioritisation, the analysis of outcomes and service gaps.

Currently, even where parents, young people and practitioners are consulted, they often do not know whether their views have been listened to and what changes have been made as a result of their input. In some areas, practitioners are still frustrated that the essential developments are not prioritised or implemented. As a result there can be a mismatch between the priorities of parents, young people and practitioners and those included in strategic plans locally and regionally.

As part of the Commissioning Standards for ASD, it would be useful to consult with parents,

young people and ASD practitioners about what they feel are the most effective mechanisms to enable them to contribute to needs analysis and to planning. It may be necessary to:

- look at new groupings for consultation and planning
- make better linkages between groups on which parents, carers and young people with ASD are represented and Children and Young People's Strategic Partnerships
- find ways of including ASD practitioners working in the voluntary and private sector to have a genuine voice in needs analysis and planning.

3. Agencies need to have in place an effective service mapping process, which looks not only at where services are and the number of people they support but also at:

- their effectiveness - both in terms of measurable outcomes and in terms of perceptions of users and their families
- their costs - broken down to make it possible to see the real costs to social care, education and particularly to health services budgets.

Factors shaping commissioning decisions for ASD services in public bodies

Commissioning decisions should be placed within a commissioning strategy. For ASD, this strategy should clearly address the distinctive issues in developing services for children with ASD.

- i. It is important that any general strategy adopted - e.g. inclusion in mainstream settings - does not outweigh or obscure the distinctive needs of children and young people with ASD. While inclusion works for some children with ASD, to include as many children with ASD & Asperger's syndrome as possible in mainstream settings is not always in their interests and - unless the school is very committed and flexible - may lead to the child experiencing failure, de-motivation, exclusion and even mental health problems. For this reason, the range of services developed should reflect the wide range of needs of children with

ASD. The commissioning strategy should drive the development of a full continuum of services available in each area and region.

ii. There is a nationally recognised shortage of skill and experience in commissioning. This problem is compounded by a lack of mutual understanding between commissioners and non-public providers of their differing needs and constraints so that relationships are often adversarial rather than co-operative. Commissioners may have a sense of failure when they resort to specialist placements in the independent sector and non-public providers often think commissioners lack knowledge of like-for-like cost comparisons, full cost recovery, Charity Commission requirements, and the realities of business.

iii. Competitive approaches are not always the most effective way of developing services. There is significant evidence locally, regionally and nationally that effective outcomes can be achieved when providers and commissioners work in strategic partnerships. Local solutions to individual need can be developed through open dialogue and innovative services can be developed by sharing resources and expertise across traditional boundaries both between professions and between public and voluntary sectors.

iv. Some well-intentioned commissioning strategies may have unintended consequences or lead to perverse incentives. Strategies may need to consider:

- Whether services should be provided by public bodies or through external partners. Commissioning orthodoxy is that competition drives up standards, creates choice and ensures prices remain good value. Therefore, if Commissioners want to achieve these goals, they need not only a managed market but an active market as well.
- Whether markets will be depressed and external services may disappear if Local Authorities respond to the increasing incidence of ASD by trying to provide the full range of children's services "in-house". Commissioners' strong commitment to the development of local expertise in ASD has not yet led to the general development of locally based children's services by Independent sector providers.

- How far Local Authorities should take the facilitator/advocate (as opposed to the provider) role - which is part of the government's agenda. Public services have often been slow to respond to the increasing incidence of ASD and Asperger's syndrome and many services have developed initially in the voluntary sector around the NAS and local branches but more recently in the private sector. There is much expertise in these organisations and a good commissioning strategy for ASD should be looking to build on this expertise rather than to replace it.

The autism-specific element of commissioning.

Commissioners need to ensure that autism-specific elements are included in their strategies. Some guidance on what should be in place at local level exists already.

- From an education perspective, the DfES has published guidance to good practice for ASD.
- From a health perspective, the NSF sets out standards for services for children and young people with ASD.
- Social care does not yet have similar nationally endorsed standards but many of the standards for education and health could apply more widely. OfSTED and CSCI have much to contribute here and may be more easily able to do so if combined in the future.

Public bodies should explicitly benchmark themselves against these specifications especially where they set out standards for delivery at local and regional level rather than for service providers

Commissioning Standards for Service Providers

Commissioning is an effective way not just to ensure minimum standards amongst providers of services, but also to establish new standards for providers to deliver and to contribute to the key task of driving up minimum standards.

This is usually achieved through accreditation of providers and through contracts, which

specify the standards to which specific aspects of the service should be delivered.

Standards which improve quality are as important to commissioners as they are for parents, young people and practitioners.

IMPROVING COMMISSIONING STANDARDS IN SERVICES FOR ADULTS WITH ASD

Transition into adulthood

The greater separation of children's from adult services under recent legislation makes it even more essential to focus on a good transition between them for people with ASD, who have great difficulties in coping with change. The best way to do this is by having good information and signposting about available resources, and a clear, viable pathway through services. Improving standards at the time of transition is critical if people are to be able to make the most of opportunities that will be available as an adult, including:

- Highly individualised and person-centred transition planning should enable a self-directed selection and funding of the services needed.
- Commissioners of adult services need to work with children's services to identify those who have statements of SEN and those who do not have a statement, but who will have significant support needs in social care, health, further and adult education etc.
- The transition plan to adult services should be developed from the person's 14th year and should include a personal health file, a health action plan, a communication passport and risk assessment, if necessary. Issues considered should include FE / HE, further training, supported employment, housing, leisure activities, on-going social skills work, life skills, social-communication development. A **key worker** should be in place to ensure a smooth route through the pathway.
- Adults with ASD, who have intellectual ability but who also have support needs should not be denied access to community resources and opportunities.
- Individuals should have a person-centred care plan and health action plan leading to an integrated assessment of their needs.

- The communication passport and risk assessment, if required, should be reviewed annually.
- All agencies should work together to give good information to families about options/choices after leaving school.

The range of services which commissioners should consider includes: speech & language therapy, occupational therapy, psychiatry, clinical psychology, counselling, gastro-enterology, dietician, community nursing, behavioural therapy, social groups, leisure services / clubs / sports, social skills groups, life skills development, purposeful daytime activities, support at FE / HE / training providers, supported employment, range of housing options, short breaks or range of respite for parents and carers, benefits and financial advice, post-diagnostic programmes for parents, access to Carers' Centres / other voluntary groups, carers' assessment, advocacy services and advocacy self help groups and behaviour intervention training for parents or carers. These services should be mainstream where possible and good training in the needs of people with autism should be provided for these professionals.

Commissioning services for adults with ASD

Practice-based commissioning

Many services for people with ASD will be purchased with local authority resources, but NHS resources will be required in some cases. Government plans to apply payment by results to virtually all NHS funded activity, so health-funded services for people with ASD, wherever they may be provided, will attract a national tariff. The government also anticipates that the future of commissioning in the NHS will largely rest with GPs through practice-based commissioning. So the future for ASD services, funded or part-funded by the NHS, may be specialised health services, purchased from a range of providers in the statutory, voluntary and private sectors, funded at least partly on the basis of a national tariff and commissioned by GP practices, probably working collectively - given the numbers of clients involved.

Some of the implications of practice-based commissioning are:

- Maximised efficiency of all providers to capitalise on the benefits of the national tariff.
- Increased importance of demand management and gatekeeping to prevent people from needing to use high cost services.
- Continued increase on the importance of community rather than hospital or other institutional settings.
- The need to maintain flexibility as practice-based commissioning develops.

Commissioning should include low-level preventative work (advice, guidance and support) to help people to avoid reaching crisis point.

However a service is commissioned, the standards that are set can only be general and it is highly recommended that no commissioner purchase or develop a service without ensuring that the recipient of the service has had the opportunity to develop a detailed person-centred plan.

Many people have found the detailed approach of Essential Lifestyle Planning helpful in learning more about the desires, needs and communication required by people with complex needs. However, this is just one of many options which can be used to support people towards the life that is right for them. Planning should be flexible and incorporate elements of different planning styles in response to what people need and want to work towards.

There is an ongoing debate about whether services should be ASD-specific or whether people with ASD can be supported in mainstream services, and about how far ASD-specific services can be localised and integrated into community living.

Most established ASD-specific services are in the independent sector of provision and have traditionally been developed in separated environments. Many parents, having gone through painful years of trying to get a diagnosis of ASD, then feel that the only way their son or daughter can be effectively supported is through an autism-specific service. We have seen the growth of family-led groups which have set up schools then developed adult provision, where all the “clients” are people with ASD. Some see this as developing providers’ expertise, others as creating a setting where autistic behaviour will be increased. People who provide more generic Learning Disability services are now able to highlight many people with autism who are supported effectively in community settings.

We suggest a debate is needed about how the specialist expertise in ASD, which has accrued in the autism-specific services, can be used strategically by commissioners to develop the competence of local and mainstream services.

Alternative options from those which are currently available should also be developed, such as personal trusts to improve financial security, use of direct payments for people to hire their own staff and to get mortgages etc, so that there is a shift of finance and power to individuals and their families and away from services. Self-directed funding and individualised budgets are the ways forward.

Designing a service specification should not only reflect the “here and now” of the person and their needs, but should also draw on historical or biographical information, where these can be obtained. Other useful information sources include – school and education records, health care records or summaries, useful family and friends’ contacts, details of significant life events, family history, culture and/or religion, risk and safety information, reason for needing a placement - leading to a person centred plan.

The Life Books which MENCAP piloted in Sheffield are a useful example of how to help families to have confidence in letting go of their sons and daughters as they grew older.

Principles on which a service should be based include:

- Services designed around the person and person-centred commissioning
- Right to services that recognise and respond to the autism-specific elements of the person’s needs and their right to have these needs met appropriately
- Personal control of individualised budget and adequate income
- Advance planning of the service provided to ensure, structure and predictability is inherent in the service environment where the person will live and work
- Health action planning
- Ownership of property
- Respecting people’s differences
- Lifelong education
- Meaningful employment opportunities
- Measures ensuring transparency of practice and methodology.

- Strong links with external professionals: in psychiatry, psychology, speech and language therapy etc.
- Established protocols for collaborative working with multidisciplinary teams.
- Valuing parents and other important family members as intrinsic to the care planning team.
- High levels of staff training and staff supervision for monitoring competence and consistency of approach.
- Building up the range of experiences people have so they can make informed and concrete choices
- Opportunities for advocacy
- External registration and external quality audit.
- Effective planning arrangements for transition to adulthood for those that need support.
- A flexible approach to people's changing needs and wishes. We all have the right to change and should not be expected to stay in a home for life.

Improving communication standards

All literature about ASD highlights communication issues. Many people with severe autism do not use language expressively and many who do use language have a great difficulty in developing the social niceties of communication and can be rigid or repetitive in their use of language. Many people with autism work on a literal use of language. A key aspect of autism is the inability to understand body language, so that the person can frequently become 'unstuck' in social situations. These problems of communication can provide a major cause of anxiety and stress for people with autism to the point of severe anxiety, panic attacks and violent behaviour.

A service with good communication standards would need to demonstrate:

- Support staff can communicate with the skills to use only a limited range of language, which is concise, clear, simple and to the point.
- The consistent use of language and terminology by everyone working with the person.
- Developing and maintaining visual prompts and augmented forms of communication, such as PECS (Picture Exchange Communication System).
- Allowing time for someone to assimilate and process information.
- Use of labelling and logical sequences of events, timetables, picture albums, keywords etc which can build up a vocabulary for the individual.
- That the people supporting the person have established a positive relationship and understand the person's method of communication.
- Use of pictures and video to prepare people for new situations and to introduce them to new staff and others, for example, virtual tours of the library, swimming baths or of a new house to reduce anxiety or digital cameras to instantly relay pictures.
- Competence in the use of assistive technology.
- The use of 'Social Stories' to prepare people for new or stressful situations. This enables the person to prepare and rehearse how to act in social situations.
- The use of TEACCH and SPELL (both are well-tested approaches to give structure to learning and to the environment). It is essential to identify the types of situation that cause anxiety and stress to the individual and to acquire expertise in techniques to deal with stress. Many people with autism find situations that others are comfortable with, are the most stressful to them. The use of the SPELL approach creates low arousal environments, but this can not always be achieved and providers should be able to use applied behavioural analysis or strategies for crisis intervention, with the assistance of a competent and knowledgeable psychologist/behaviour therapist.
- Risk management strategies to address known difficult behaviours or likely reactions to stressful environments. Any strategies should be developed from the person-centred plans and allow sufficient space so that people are not over-protected or over-managed with well meaning but intimidating support staff. The reaction to having 1:1 or 2:1 staffing is often inappropriate and more likely to create further negative reactions. People with autism generally need to enjoy their own personal space and privacy.
- Development of the person's social networks, including mapping local resources and community/interest groups, using mainstream activities and facilities and developing links with local clubs, societies and groups especially

where there is an opportunity to pursue the person's special interest.

Standards to improve the service environment

Environmental factors shape the choices which are open to people, whether they live within a group of self-contained flats, or in houses bought via a mortgage, in supported tenancies or in residential care.

Funding for community-based support should make best use of a range of funding streams including the Independent Living Fund and Supporting People.

The development of small groups of flats/apartments appears to offer a reasonable compromise in providing personal space, yet has the efficiency of staffing and the oversight to ensure that social isolation does not occur. However, any service that accommodates several people in a single house is unlikely to be able to offer personal attention and may easily fall prey to allowing the lowest staffing levels.

A low arousal environment should be given high priority. Sensory issues are emphasised in personal accounts by adults with ASD and over-arousal is a major source of stress. A regular audit of noise levels should lead to a minimum of intrusive noise, and to noisy activities, such as vacuum cleaning, being carried out when residents are absent. A sense of personal space and lack of clutter in the environment is helpful, as is the use of colours which are not vivid or clashing. Fluorescent lights, where they are needed, should be 'daylight' tubes and the use of aerosol air fresheners should be limited. Sensory rooms are helpful in reducing anxiety, and it is always necessary to assess the individual's particular sensory sensitivities.

Access to music and art therapies, light-rooms and sensory integration programmes have all proved to be valuable in counteracting the effects of ASD.

Standards in building design

In considering physical aspects of building design, layout and materials, the following should be considered:

- The building as a whole, and the rooms within it, should have a simple and uncluttered layout.
- There should be ample space, particularly in any shared residential setting, since

people may find passing others in narrow spaces is extremely anxiety-provoking.

- Buildings should have acoustic properties to minimise noise, and keep any background noise to a minimum.
- Although the person should be helped to choose furniture and fittings as far as possible, the use of calming, plain colours and simple, clear shapes may be helpful.
- Lath and plaster walls should be avoided, since they can be easily dug into, and curtains with Velcro are useful, so that if they get pulled, the whole fitting will not be destroyed

Standards to improve staff skills and training

Any service will show its competence through the skills and knowledge of its staff at all levels. Reactions which would be appropriate in working with others can be just the opposite in working with people with autism. Good quality and on-going staff training and management supervision of practice is essential.

Staff must have training in:

- Awareness and features of autism
- Communication techniques
- Anxiety management
- Risk management

In order to develop personalised services, as opposed to the person moving into a home 'provided by' someone else, the following standards would apply and staff should be competent to ensure that:

- Suitable financial advice is available
- A personal trust has been established to manage a person's finances using suitable financial advice.
- A personal plan has been developed and costed.
- The person is able to make choices about accommodation (rented, bought, shared ownership etc).
- The person has suitable flatmates / tenants.
- The person has support around employment options.
- The person is able to hire & fire their own staff support.

What would a model range of provision look like?

A model range of services for adults would enable people to make choices about their lives and lifestyles and would help promote people's sense of independence and social inclusion in ways that are important for them.

The commitment to individualised and self-directed services suggests that the idea of having a prescriptive range of services is not a helpful way forward. There are however basic assumptions which should underpin the development of services.

- Support services should, wherever possible, be local services and based on good preventative support with specialist expertise, thus reducing reliance on specialist out-of-area placements.
- ASD-specialist posts, e.g. in clinical psychology or speech and language therapy, will support the development of autism-competence in local services.
- A model range of provision will emerge from partnership working between statutory services, families and individuals, and providers.
- Localities need more competent mainstream (non-specialist) services to support people with autism.
- Strategic commissioners will continue to need to ensure that an appropriate choice of services is available and that those services have the relative financial stability to survive the ebbs and flows of individual clients' investment.

What infrastructure is needed to support a model range of provision? What standards should commissioners aspire to?

- Given the wide range of abilities across the autism spectrum, commissioners need good quality, shared information about current and future demand for support. Localities should have robust systems for the collection and dissemination of information about the needs of people with autism. It is very difficult for adults with ASD to obtain a diagnosis. Whilst this need not be an essential requirement in order to gain access to other services, screening for ASD should be increased. The screening measure which has been developed in the North West can be found on www.autism.org.uk/screening.

- Co-ordinated planning across agencies and in partnership with parents and the voluntary sector needs to be in place, particularly at the time of transition to adulthood. Mainstream services should be part of this.

- Multi-agency Autism Services Development Groups are needed in each local area. They should be wider than the health/social care matrix and should include the LSC, Connexions, Job Centre Plus etc. Family members should also be included.

Planning needs to be plugged into a commissioning structure through Partnership Boards and through Autism Services Development Groups in each locality. Mainstream resources should be included and should have the capacity of being used flexibly. A jointly agreed commissioning strategy should be in place with leadership from statutory sector senior managers to ensure that commissioning pathways are transparent.

- Good data collection and mapping of provision, shared within and across organisations, are vital to the success of person-centred planning. They should include present commissioning activity, whether screening for ASD is carried out.
- Groups should work together regionally and should consider developing commissioning consortia.

- I In the North West, 17 local authorities have multi-agency Autism Services Development Groups in place. In the North East, 12 authorities have agreed to set up a regional Autism Consortium, which will focus on strategic commissioning. So 22 of the authorities in the North work within regional autism consortia.

- Co-ordinated assessment and care planning needs to link with person-centred planning. A framework for improving the take-up of person-centred plans should be in place.
- Families and individuals need access to good quality information and guidance in shaping the most appropriate support

package for themselves. Information needs to be about opportunities and resources available rather than simply about the services themselves. Peer support networks should be in place. Pathways to accessing support services should be available.

- A training strategy for all service providers should be in place to provide a competent workforce within the locality. This includes awareness-raising for all staff, further training for some staff and a third tier of specialist training as required. The training strategy must include housing, leisure and education support workers. Learning & Skills Councils should be encouraging Colleges to help develop the competent workforce.

What sort of services need to be in place?

- Services should be accessible, inclusive and locally-based. They should support choice and flexible, person-centred or self-directed activities. Services will need to provide experiences and support activities in such a way that meets people's needs for:-
 - structure and routine, continuity and predictability
 - intensive support during unstructured periods
 - close attention to people's sensory reactions
 - clear and uncluttered verbal communication
 - consistency of approach by support workers
 - improved anxiety management skills.
- The range of provision will need to encompass intensive support to some people relating to accommodation and daytime activities through to access support to enable people to take up employment, further education, leisure and housing opportunities. Therapeutic support should be available where required.
- Services should provide more employment opportunities for people with ASD. The commissioning strategy should ensure that there is sufficient opportunity for people with ASD to be prepared for and to take up paid or unpaid employment .

- There is likely to be a mixture of specialist and mainstream service providers. Where specific specialist services are required, commissioning across localities in a consortium should be considered.
- There may be a role for a super specialist agency, acting as a regional resource to help local services take on more complex work and support staff.
- There is a clear role for the voluntary sector in a model range of services, not only as a provider but also as both a lobbyist and champion of good quality services. Service commissioners should support networking across voluntary agencies.
- A model range of service should be able to reach out to people from minority ethnic communities to ensure they receive culturally appropriate support services and that they have every opportunity to influence and shape the sort of services they want.

Gaining the perspectives of parents and of people with ASD

The lip service which has long been paid to partnership with parents in professional practice has led to a lack of trust by many parents who have entered into partnership working. This has to be turned around, if we are to move forward.

Many parents want to be involved in the development of services, but feel that their views will not be listened to and that the process of consultation is just a paper exercise. Others simply do not have the time. They work during the day and have childcare commitments outside work, or the stress of their caring responsibilities leave energy for little else. Many mistakes have been made in the past in relation to consulting with parents and changing their perceptions will not be easy. The attitudes of some professionals have led parents to be more confrontational and adversarial, and to have little sense of working in partnership.

One set of questions relates to how and where we can gain parental perspectives. Do agencies keep asking the same parents to be involved in consultation time and again? Do we hold one meeting or several? If we are

looking to gain the perspectives of groups of parents, do we ask parent/carer groups for representation, despite the difficulties of representing a wide range of views and experience? Some parents find difficulty in expressing their views in a public meeting and disgruntled parents may be more likely to make the effort to have their views heard. Each child is an individual and parents are looking for different things. Do they have enough information to know what they are looking for? Many parents feel that they receive no help or support from current services, so is it fair to ask them to help shape the services of the future?

Many parents will have expectations and ideas about the sort of service they want for their son/daughter and these need to be identified and any potential issues resolved by the Care Manager. Many parents are aware of techniques and approaches which are used in the field of autism, many of which are not validated by research, or may not be used in particular service settings. Some parents expect that a service which claims autism as a speciality will use approaches or therapies which have been publicised as relevant to autism, but are of little or no proven value, such as secretin, swimming with dolphins or megavitamin therapy. Clarity from the outset can prevent later disputes.

Parents need to be confident that there is a process of work underway and one in which they are a part. They need to have the confidence that decisions are not already made before they have had a chance to give their opinion and that it is worth them giving up their time to get involved. There should be an ongoing dialogue.

What good practice standards apply in consulting with groups?

Consultation should be viewed as a series of meetings. Parents need feedback in order to know that their views are being taken forward, or if not, why not.

Groups of parents and carers need opportunities to take their issues to wider partnerships and to network with other groups. Professionals should help them to do this.

Commissioners should arrange to pay an hourly rate and expenses both for parents and for individuals with ASD when involving them as a resource in partnership working, if they are to feel their contribution is respected and truly valued.

Commissioners and planners should be able to offer a choice of ways in which people can take part, e.g. meetings, email, questionnaire, internet conferences etc. Meetings do not work for everyone.

... and in consulting with people who have autism?

Consultation should include and involve people from across the whole spectrum of autism, without relying on the people who always get asked because they have good verbal skills.

People need a choice of ways to be involved, for example through advocacy groups, or the use of e-mail if they prefer not to communicate directly.

The NAS has produced guidance about how to comply with the duty, under disability equality legislation, to involve and consult people who have ASD.

Accreditation and Quality Standards

General accreditation schemes.

Across the UK, authorities are working together in regional and supra-regional clusters to develop common accreditation and contracting arrangements. At present these tend to be focused on achieving minimum standards.

While local development gives ownership, there is duplication of effort. A good commissioning strategy would recognise this and support national schemes. This is particularly important for ASD where the most specialised resources serve a national rather than a regional catchment area.

Accreditation for improvement

When accreditation and inspection work well, they serve as development tools to raise standards further.

i. General Inspection Regimes.

Most local authority contract/ monitoring schemes are technically concerned with finances and fitness to run a service rather than the quality which is generally judged through national inspection outcomes from CSCI and OfSTED.

Where there is an outreach support service rather than a home or school/college for young people with autism, the DfES/DoH guidance on good practice for children and young people with ASD will be relevant although it is not clear whether quality would be evaluated through self assessment or inspection.

ii. Autism Specific Accreditation

The government's Better Regulation Task Force has recently recommended that specialist services should have specialist external accreditation and that, where this applies, other forms of regulation should be minimal.

This recognises that general inspection approaches can be rather blunt instruments for assessing the quality of services for people with ASD or Asperger's syndrome, the outcome measures used are often not those which would be prioritised people with ASD.

There needs to be a more effective way to measure how autism-specific a service is and how far it is able to deliver outcomes that are meaningful to children and young people with ASD and their families.

The DfES/DoH guidance on good practice gives detailed standards against which providers of children's services could be assessed or could self assess. While there are multi-agency aspects to the standards /

pointers to good practice, on the whole they are education focused and not easily applicable to other settings.

The other weakness is that it is a self-assessment tool and does not have a moderated, external element that is robust enough to be used for commissioning.

Arguably, an autism-specific quality assurance tool with this sort of external validation already exists in the NAS Autism Accreditation programme. It covers a wide range of autism-specific indicators and is effectively a kite mark for an ASD service. It is also applicable across the whole range of services for children and for adults.

Rather than invent a new system, Commissioners could start to expect all services they purchase to have Autism Accreditation. For new services or existing services without accreditation, there could be an expectation that the service would achieve this in 2-3 years at the latest.

Since the quality of services is likely to be quite different, the NAS accreditation programme needs to develop a more differentiated scheme. Levels of accreditation would recognise not only good practice but excellent practice too.

Since this approach would give providers something to which they can aspire as well as support the delivery of good quality services, it is logical to support this rather than to encourage authorities to seek to improve standards through imposing separate contractual conditions based on what they consider to be good practice.

Improving Commissioning Standards in Services for Children and Adults with Autism Spectrum Disorders

Recommendations

1. Joint strategic commissioning across health and local government areas should be strengthened in services for children and adults. Directors of Adult Social Services should ensure that effective commissioning is developed and improved in response to the needs of adults with ASD. (ref: paragraph 15 of statutory guidance issued in May 2006)

2. The infrastructure to enable this development to take place should be at three levels; regional ASD consortia, local Autism Services Development Groups (ASDGs) and key local stakeholder groups to work on specific issues.

The consortia should bring together the work of the local development groups in order to implement a regional commissioning strategy and to make the most effective use of resources in their region.

The multi-agency ASDGs, which should include commissioners and senior managers from statutory services, should ensure that good standards and good quality services are in place. They should have the capacity to champion new developments, to ensure continuous improvement in standards and to ensure that funding is ring-fenced for pooling purposes.

Local groups should be appointed by their ASDG to work for a specified period on an area of high priority in services development. They should comprise those who have the greatest stake in this area of development, including practitioners from any sector of provision, family members and people with ASD. The ASDG should use the groups' recommendations in the development of their commissioning strategy.

The members of the ASDGs in the region should meet annually to review their progress and to plan development in the coming year. Two regional networks in the North West will co-ordinate the work of the chairs of the ASDGs in the region, and the involvement of people with ASD. They are facilitated by the NAS (see Appendix for contact details and terms of reference of ASDGs).

3. In order to develop the competence and cost-effectiveness of local and mainstream services, commissioners should lead a joint contracting process, locally and regionally, to make the best strategic use of the specialist expertise in ASD which has accrued in the autism-specific services in the independent sector.

4. Commissioners should invest creatively to enable family members and self-advocacy groups to support and inform the commissioning process, including funding of ASD-specific development work.

5. No service should be commissioned or purchased without ensuring that the recipients of the service have each had the opportunity to develop a detailed person-centred plan, which should then inform the service specification and provide a local wrap-around service with an individualised budget.

6. Existing standards relating to local children's services should be drawn together by the Care Services Improvement Partnership (CSIP) to form a self

assessment tool for Children's Trusts in commissioning services for children and young people with ASD and for their families. The CAMHS development strategy should focus on the prevention of the need to commission tier 4 services, by strengthening services in other tiers, but also by ensuring equitable provision of tier 4 services.

7. Agencies which commission services and Connexions should have a clear set of standards in relation to transitional planning to ensure that people across the autism spectrum are supported into adulthood, including many people with Asperger's syndrome in mainstream schools who need effective post-school support.

8. Accreditation of the autism-specific elements of services should be provided, for example through NAS Autism Accreditation which is increasingly used in local and mainstream services. Accreditation should be developed to reflect, for example, individualised budgets and to provide assurance of quality at different levels. Where a service is not accredited, commissioners need to ensure that the care plan identifies the required ASD-related outcomes for the individual.

9. Micro-commissioning at Care Manager level in adult services should be strengthened. Adult Social Services should ensure that training in assessment and person-centred working re. ASD is provided for Care Managers as a priority, to enable them to undertake good quality assessments and support person centred planning and self-directed services. Commissioners at this level should ensure that providers are also equipped with this information and out-of-area and high cost placements should be continuously reviewed so that plans to return closer to home become a real option.

10. Commissioners should ensure that they identify people with ASD who are at risk of offending. They should work in partnership with colleagues from the criminal justice system to prevent offending. Their partnership should ensure opportunities for shared learning so that competence in ASD and criminal justice is developed across the workforce.

Footnotes

A systematic review of the comparative benefits and costs of models of providing residential and vocational supports to adults with ASD has also been carried out by Lancaster University, as a parallel piece of work linked to this paper. It recommends that "commissioning, provider and advocacy agencies (whether on a national or regional basis) explore the possibilities of collaborating to encourage the development of practice-based evidence. This could involve, for example, agreements to pool information on the costs and outcomes of residential or vocational services across geographical and sectoral boundaries".

This paper and the review are published on the National Autistic Society website: www.nas.org.uk

A series of linked initiatives across the North of England include the following:

- **The North West Centre of Excellence supports an initiative to pool information about high cost placements in the region. This should lead to a broader regional commissioning strategy, particularly re. ASD as recommended in this paper.**
- **The 12 local authorities in the North East and the coterminous North East Strategic Health Authority are establishing a North East Autism Consortium which will be responsible for the development of a regional commissioning strategy, similar to that proposed here. The North East Centre of Excellence is funding the establishment of the consortium, which will have a network of Autism Services Development Groups, supported by the National Autistic Society, as in the North West.**

North West Autism Commissioning Standards Working Group

Membership

Nick Morey (Chair)	Integrated Commissioning Manager, Bury MBC and PCT
Brenda Nally (Facilitator)	Regional Co-ordinator, National Autistic Society
Janet Cobb	Consultant, North West Training and Development Team
Val Cumine	Autism Specialist, Lancashire LEA
Halcyon Edwards	Greater Manchester SHA
Helen Garry	Commissioning Manager, Cheshire West PCT
Helen Hewitt	Director of Education, Together Trust
Clare Hughes	Regional Officer, National Autistic Society
Ann Jones	Regional Development Worker, LD/CAMHS, North West
Beth Matthews	Director of Education, Autism Initiatives
Michelle Montrose	Commissioning and Development Manager, Liverpool
Chris O'Gorman	Head of Joint Mental Health Commissioning, Central Manchester PCT
Barry Probin	Advisor, Lancashire LEA
Don Rowbottom	Policy Officer, Lancashire County Council HQ
Paul Sutton	Area Manager, National Autistic Society
Barbara Taylor	Advisor, Sefton LEA

Appendix

GOOD PRACTICE GUIDANCE FOR AUTISM SERVICES DEVELOPMENT GROUPS

The work and structure of the autism services development groups (ASDGs) in each locality was discussed with all of the chairs of ASDGs across the north west during interviews to ascertain where each area was in terms of the recommendations of the North West Autism Task Group Report. It became apparent that the chairs and other members of the ASDGs recognised that there was a need to facilitate the process of development and the work of the group. This document has therefore been produced in response to this and from comments gained. It would seem through these interviews that an effective ASDG would incorporate the following elements. This document is not meant to be a prescriptive or exhaustive list of instructions for ASDGs. Instead, it is meant to be a benchmark for groups to aspire to and to help each group to establish its terms of reference. There will be many aspects that groups in the region are already achieving.

Mission Statement

To improve access to better local services by all people with an autism spectrum disorder (ASD) and their families, members of ASDGs would work together towards:-

Function

- addressing the needs of all individuals with an ASD and their families/carers across the spectrum and across the age range.
- ensuring all members are clear what their responsibilities are, in relation to service development, and make a commitment to being a member of an ASDG.
- working towards the collective targets and agenda set by the regional consortium, (in Greater Manchester) and developing these collective targets elsewhere in the region. This must be carried out within regional and national policy initiatives.
- gathering evidence in their locality of the need for development of services e.g. projected school leavers with an ASD and their associated needs for services as adults
- setting achievable targets and prioritising them.
- gaining knowledge about and linking in to other existing groups that are not autism specific, but which have a responsibility to look at issues which would have an impact on the lives of people with an ASD e.g. housing, transition, leisure, etc. The group will establish ways to promote the needs of people with an ASD and ensure that autism is kept on the agenda within these non-specific groups.

Mandate

- providing the infrastructure to enable Directors of Adult Social Services to ensure that effective commissioning is developed and improved in response to the needs of adults with ASD. (ref: paragraph 15 of statutory guidance issued in May 2006)
- ensuring that good standards and good quality services are in place. The groups should have the capacity to champion new developments, to ensure continuous improvement in standards and to ensure that funding is ring-fenced for pooling purposes.¹
- securing a mandate for the chair and for the members of the group.
- providing a clear mandate to their working groups including an agreed timescale of work.
- promoting effective commissioning by using links with other ASDGs to ensure collective strategic planning and regional delivery, where appropriate.

¹ Taken from the report, 'Improving Commissioning Standards in Services for Children and Adults with Autism Spectrum Disorders'. Available on the NAS website www.autism.org.uk

Membership

- identifying a deputy chair that would attend meetings alongside the chair and would take on the role of the chair in their absence. The deputy chair would ideally work within a different agency from the chair.
- ensuring the core membership includes representatives from education, health, social care, parents/carers and where appropriate, service users.
- ensuring that commissioners work within the group. When this is not possible, the chair should ensure that they have a direct link to them.
- having meaningful parental involvement in the group. Where possible, parental representatives should be linked to a parent/carer support group.
- addressing the best ways to consult with those with an ASD in their area.
- engaging elected members and sending them minutes.
- working with existing voluntary and statutory services, both specialist and mainstream, to improve access to **all** services for people with an ASD and their families.
- having an annual review of its membership, to ensure that the right people at the right level are involved in the group.

Process

- working within its terms of reference.
- distributing an agenda and minutes prior to each meeting.