

AUTISTIC SPECTRUM DISORDERS

Background

1. From its outset, the Bamford Review of Mental Health and Learning Disability (NI) has recognised that people with an Autistic Spectrum Disorder (ASD) have a wide variety of needs, some of which are currently being met within learning disability services, some within mental health services, some within other programmes and some needs are not being met at all. By way of illustration, in Priorities for Action 2003/2004 autism is referenced in three separate service areas - mental health, learning disability and child health.
2. The Review has given serious consideration to how the needs of people with ASD should be met. At the core of the Review's deliberations has been determining how the range of effects of autism can best be addressed and the consequent diversity of required interventions developed within the two components of the Review i.e. mental health and learning disability.
3. Reports from individual Review Committees are addressing the needs of people with ASD within their respective remits. For example, the Adult Mental Health Expert Working Committee report includes a section on 'Services for People with Asperger's Syndrome or High Functioning Autism' with related recommendations. The 'Equal Lives' document on Learning Disability also makes reference to the complex needs of those with both a learning disability and autism. However, it was concluded that the needs of all those with an ASD and their carers should be the subject of a separate and overarching paper by the Review.
4. In compiling the following framework for the future development of comprehensive autism specific services, it was acknowledged that excellent and expert guidance has been issued in recent years. The Review gave due consideration to several national and regional documents.
5. To inform the Review's work on ASD, a major stakeholder event was held in December 2004 to establish priority needs for service development in Northern Ireland. Workshops considered the needs of children and adults who have autism, those with a learning disability and those who do not have an intellectual impairment, compiling an agreed list of priorities. Common and recurrent themes that emerged from each workshop form the basis of this policy framework for the future development of autism specific services.
6. The Review has deliberately provided broad recommendations for future service development, recognising that Health and Social Services Boards and Trusts are at different stages in current provision. However, the key recommendation of the Review is that a senior

manager in each Trust should be given responsibility for the development of autism specific services and the co-ordination of these across programmes of care. Service provision for ASD must embrace partnership approaches that integrate and provide a whole systems approach, so collaboration with other relevant agencies such as education authorities will be an important component of the manager's role. Those identified as having responsibility for ASD should consult respected documentation that has been published previously if more detail is required. A needs assessment of people with ASD and their families should be completed as a priority.

New funding must be prioritised to underpin the Review's recommendations on ASD services.

Key Areas for Service Development

1. Assessment and Diagnosis

Timely and accurate assessment and diagnosis is a vital first step in meeting the needs of people with ASD and minimising the adverse effects of the condition. Delay in diagnosis is often attributable to poor co-ordination and fragmentation of services. There is increasing evidence that diagnosis is more accurate and can be achieved at an earlier age (ideally around 2-3 years) where assessment is multi-disciplinary and ASD specific. Evidence-based models of practice advocate an intensive diagnostic approach with both child and family in attendance with assessment being undertaken by a range of specific practitioners from relevant agencies.

While much of the work should be concentrated on early assessment in young children, the assessment needs of older children and adults must not be ignored. Knowledge of the size of the challenge in adulthood (its epidemiology, the number and kinds of services that would be needed) is poor, but likely to improve rapidly over the coming years. Expertise in relation to adults with Asperger's Syndrome/High Functioning Autism is lacking and needs to be developed.

Recommendations

- Autism specific diagnostic and assessment services must be established in each Trust.
- Providers should offer ASD specific diagnostic and assessment services for children and adults, regardless of intellectual ability.
- Professionals involved in this work must be highly trained, skilled and experienced in child development and in relevant disorders including mental health problems.
- Expertise in relation to adults with Asperger's Syndrome/High Functioning Autism needs to be developed.
- Child and Adolescent Mental Health professionals must acquire greater knowledge and experience in assessment and diagnosis of ASD.
- There should be a clear pathway to diagnostic and assessment services for families once ASD is suspected.
- Quality standards for the process of assessment and diagnosis are required to ensure consistent good practice.

2. Intervention

Diagnosis should act as the stimulus for provision of a range of appropriate interventions in response to the assessed needs of people with ASD and their families. As with assessment, a co-ordinated approach and multi-disciplinary working are essential.

Recommendations

- All children and adults receiving a diagnosis of ASD must be offered appropriate and timely intervention based on best available evidence.
- These must be person-centred, delivered by adequately trained practitioners and provided on an inter-agency basis, as appropriate.
- A 'keyworker' model should be developed for each individual with ASD and their family/carers, to ensure access to autism specific services and any other services that may be required.
- There must be a clear referral pathway to appropriate mainstream services that may be required by a child or adult with ASD.
- For some, specialist medical care and intervention will be required as appropriate. People with autism should receive this from medical practitioners trained in an understanding of autism.
- A wide range of interventions will be required to meet the spectrum of needs presented by children and adults with autism.
- Those responsible for service commissioning and delivery will need to keep abreast of current developments, research and efficacy of interventions for autism.

3. Individual and Family Support

Services must be person-centred and recognise the importance of work, leisure and social activities to the person's health and wellbeing. There is a need for forward planning and good co-operation between services at key transition stages of life.

Service providers must also recognise the valuable contribution being made by families and other carers and seek to provide information and support to them in their role. Respite services, which may range from youth clubs, play and befriending schemes to family based or residential breaks, are central to supporting families.

Recommendations

- Emotional and practical support for the individual and their family must follow confirmation of diagnosis in a timely fashion.
- Particular attention must be given to supporting the individual and their family during 'transition' times. For example, primary to secondary school, leaving school, moving away from the parental home.
- Careful planning will be needed particularly for transition between child and adult services to ensure continuation of the support required in adulthood.
- Respite services require to be developed by specialist, mainstream and voluntary sector services as appropriate.
- Respite should be planned in advance and not reactive to family crises.
- All children and adults with autism should have access to leisure and meaningful activity tailored to their needs and interests that promotes social inclusion.
- Support is required for children to develop their social skills and understanding.
- Adults should be able to access social groups developed with their participation and tailored to their needs and interests. These will aim to help them learn how to form relationships, develop community and social skills.
- Adults with autism who wish to receive further and higher education should be supported to do so through the provision of educational and support services. These must reflect the needs of students with autism through person-centred assessment.
- Assistance for adults in finding an appropriate job, with access to autism-specific employment advice and support needs to be developed in their local area. (The Disability Discrimination Act now requires that employers make 'reasonable adjustments' to reduce and remove any substantial disadvantage to a disabled employee or job applicant.)
- A range of supported accommodation options to meet the needs of current and future adults in their area must be developed.
- The model of 'care planning' and 'care management' should be adopted to support the individual with ASD and their family or carers.

4. Training

Staff delivering services to people with ASD and their families must be adequately trained to ensure they are competent for the task. In addition, families and carers need training to fulfil their role. Better general awareness of ASD among primary care and community staff, especially those dealing with young children, would enhance recognition of problems and facilitate earlier referral for assessment.

Recommendations

- A regional training strategy for parents and staff must be developed.
- Two tiers of training are necessary – awareness and specialist training.
- An awareness training programme should be available to all staff in contact with children or adults with ASD who require a basic understanding of the condition.
- Basic awareness training at pre-qualification level for professionals likely to come into contact with people who have an ASD should become standard practice.
- Specialist training is essential for those involved in diagnostic assessment of ASD and/or intervention for individuals with ASD and their families or carers.
- Training should be delivered by professionals who are ‘accredited’ or have recognised expertise in ASD to ensure quality is maintained.

5. Management and Co-ordination of ASD Services

The Review wishes to see an integrated service for people with ASD which builds on existing services to provide a more comprehensive and coherent response to need. Strategic direction for such service development is essential and the Review, therefore, recommends that a senior manager should be identified in each provider unit to assume overall responsibility for ASD services for both children and adults. Service development plans should be informed by robust needs assessment.

Recommendations

- A senior manager in each provider unit should have overall responsibility for the development and coordination of services for children and adults with ASD.
- He/she will ensure the development of autism specific services within existing programmes of care - community, mental health, learning disability and children's services, including child and adolescent mental health.
- It will be his/her responsibility to set up a co-ordinating group for strategic planning, audit and evaluation of ASD services.
- A major role will be to involve and co-ordinate relevant statutory and voluntary agencies in provision of services for people with ASD and their families or carers.
- Each provider should develop adequate information systems to assess need and inform future planning services at local and regional level.

6. Responsibility for ASD Services

The needs of people with ASD are varied and current service responses span several programmes of care. This can result in lack of co-ordination of services and poor impetus for service development. The Review considers that the creation of a separate programme of care would, among other things, divert scarce and much needed resources from the development of direct service provision for those affected by ASD and could lead to further marginalisation of people with ASD. However, it is imperative that the existing programmes of care structure do not impede future development of, or access to, autism specific services.

Implementation of the Review's recommendations depends on robust commissioning services, both regionally and at local level.

While much of the emphasis for assessment will properly focus on children and younger people, the life-long nature of the condition means that the need for services will continue into adulthood.

Recommendations

- Commissioners of services must ensure that providers specify organisational responsibility for implementation of ASD services across all programmes of care.
- The Review recommends that the Learning Disability Programme should be responsible for service development for those with ASD and learning disability; the Children's Services Programme for children and young people with ASD; and the Mental Health Services Programme for adults with ASD.

Relevant national and regional documents on ASD

Taking Responsibility

Good practice guidelines for services – adults with Asperger Syndrome.
National Autistic Society, 2002.

The National Autism Plan for Children.

National Initiative for Autism: Screening and Assessment (NIASA), 2003.

All Party Parliamentary Group on Autism (APPGA), Manifesto Principles.

National Autistic Society, 2003.

Report of the Task Group on Autism.

Department of Education for Northern Ireland, 2002.

Priorities For Action 2003/2004.

DHSSPS, 2003.

Development of ASD Services: Diagnosis & Early Intervention.