



The Blueprint for Change



This document is the latest product of the accelerating Northern Ireland political lobby and campaign to progress social justice and equality for individuals with an Autistic Spectrum Disorder in recognition of the unique vulnerability and under-resourcing faced by this section of our community.

The campaign, which commenced in 2002 with the creation of the MLA network of NI Assembly Autism Ambassadors, has recently attracted the interest of the Secretary of State for Northern Ireland and has initiated partnerships in Northern Ireland (e.g. SPEAC, CEAT, NIPPA, Autism Initiatives) as well as in Wales, Scotland and Sweden, as it builds up its irresistible case for dynamic change locally.

The Blueprint sets out the underpinning issues that must not be compromised as we move into the next critical stage of empowering our political and public representatives to shape innovative legislation for Northern Ireland.

It is important to note that the Blueprint does not seek to replicate existing legislation; but rather addresses the unique issues facing individuals with ASD and their carers that existing legislation does not reach.

This document builds upon “Government and Autism Opportunities and Solutions” report launched in Whitehall in March 2006.

The Blueprint for Change

Autistic Spectrum Disorder (ASD) will be recognised by government, health, education and the community at large as a complex, lifelong, developmental disability. Autistic Spectrum Disorder is not a learning disability or a mental health problem.

The government will set up a Northern Ireland ASD Strategy comprising of:

1. A policy on raising awareness of the issues faced by people with ASD and their families.
2. A dedicated programme of care providing for children and adults with ASD.
3. A funding strategy to underpin the transition to a separate programme of care for Autism. This funding will be reviewed regularly and will be based upon a 3-5year funding term linked to operational ASD service plans.

Identifying Individuals with an ASD

4. All staff working with children and adults should be alert to the presenting features of ASD.
5. A mechanism will be put in place to enable health and education professionals to quickly respond to concerns regarding ASD.
6. A clear referral route for children will be established as described in the National Autism Plan for Children (National Initiative for Autism Screening and Assessment NIASA, 2003).
7. A referral route for adults will be determined and established.
8. A named key worker will be appointed at the time of referral for diagnosis for both children and adults. The role of the key worker will be manifold and will address key transition periods;
 - a) The key worker will provide support to families at the point of referral; offering information on the diagnostic process; assisting families with any transport or access issues in attending hospital appointments and follow ups.

- b) For children and pre-schoolers the key worker will provide access to locally based pre-diagnosis interventions i.e. Rainbow Resource Kits and training.
- c) The key worker will offer advice for the individual and their family throughout the diagnostic process, post diagnostic intervention and development of an individualised care plan.
- d) The key worker will liaise with local voluntary and statutory organisations where appropriate to provide information and or services.

Diagnosis and Intervention

- 9. Adequately resourced multi-agency and multi-disciplinary teams comprised of appropriate ASD specialist health care professionals will be established to provide comprehensive and accessible diagnostic services for all ages. (N Ireland Diagnostic Scoping Study, Autism NI (PAPA) and University of Ulster, 1998)
- 10. The diagnostic team will include at least one member who has received recognised specialist training in the assessment and diagnosis of ASD. All other members of the team will have received ASD specific training.
- 11. Diagnosis can be given by any NHS / Department of Education professional who has received and completed recognised specialist professional diagnostic training and has regularly updated this training and who are accredited with their appropriate professional body.
- 12. A needs led care plan will be implemented within 6 weeks of diagnosis; this care plan will take into consideration national and local good practice i.e. Connecting with Autism, Autism NI (PAPA) 2006; Keyhole, Autism

NI (PAPA) and University of Ulster, 2003; Task Group Report on Autism, Department of Education N Ireland, 2002; Autistic Spectrum Disorders a Guide to Services for Adults, Foundation for people with Learning Disabilities, 2001; N Ireland Diagnostic Scoping Study Autism NI (PAPA) and University of Ulster, 1998.

- 13. Access to laboratory investigations will be available in order that an underlying medical explanation can be eliminated. Genetic counselling will be made available if desired.
- 14. Funding will be made available for relevant targeted research that adheres to the guidelines for good practice for research in ASD, (N Ireland Diagnostic Scoping Study, Autism NI (PAPA) and University of Ulster, 1998)

Training

- 15. Organisations providing education and or caring services have a legal responsibility to ensure staff in direct contact with individuals with ASD receive appropriate accredited training.
- 16. Organisations will ensure that training in ASD is refreshed annually and where appropriate is incorporated into the continuing professional development of staff.
- 17. Training in recognising ASD will be made part of the professional training of all frontline health and education professionals.
- 18. Training in ASD will be made available for parents / carers / spouses / partners of individuals with ASD.
- 19. Training and information on ASD will be made available to key decision makers in benefit agencies.

20. General ASD awareness training and support will be made available for organisations / employers who are in contact with individuals with ASD.
21. A funding pool will be made available for organisations wishing to access training.

Health

22. Primary healthcare providers will be aware of the complex communicative, social and sensory issues with ASD. How ASD can be a barrier to diagnosis of physical malaise; and how this will effect their treatment i.e. a fast track system/private rooms.
23. Healthcare providers will facilitate and resource access to professionals allied to health for individuals with ASD; this will take the form of:
 - a.) Timely access to Allied Health professionals.
 - b.) Recognition that the presence of an ASD may result in an increased need to access health care services e.g. sensory issues, mental health issues.

Education

24. Educational institutions from pre-school to further and higher education will adhere to the recommendations made by the Task group Report on Autism (Department of Education Northern Ireland, 2002). These recommendations will change from being advice to being incorporated into legislation
25. Education will provide individuals with ASD with appropriate social skills and life skills training.
26. Individuals with an ASD and their teachers will have access to a specialist ASD advisor within one week of a parent or professional referral whether or not they have a statement of educational need.

27. Provision for appropriate post 16 education will be available for individuals with an ASD.

Families

28. Respite will be provided and tailored to individual family's needs.
29. Individuals with an ASD will have access to independent or supported living.
30. Benefit assessment for an individual with an ASD and their carer will be equitable, and provided for by mandatory ASD training for Decision Makers in the Social Security Agency.
31. Family and individual support will be delivered by key voluntary organisations and voluntary and statutory partnerships.
32. Recurrent funding will be made available for voluntary organisations and voluntary / statutory partnerships for ongoing support work and innovative projects.

Criminal Justice

33. All members of staff within the criminal justice system who are likely to encounter individuals with ASD will receive ASD training.
34. Appropriate detention, custody and interview accommodation will be available.
35. Appropriate intervention strategies will be adopted and put into place.