

Autism

Support across the Lifespan

Regional Autistic Spectrum Disorder Network (RASDN)

Updated February 2013

1.0 INTRODUCTION

1.1 Strategic Context

The term Autistic Spectrum Disorder (ASD) describes the social and communication behaviours, and the unusual and/or repetitive behaviours of a group of children, young people and adults.

“Since ASD is a diverse condition with a wide range of impairment, age at diagnosis, intellectual ability, personal needs and health status, a range of customised supports and services will be needed.” (Ref: New Zealand Autistic Spectrum Guide, 2008)

There are a number of specific strategic drivers that must be considered when developing guidance to meet the support needs of children, young people, adults, parents, carers and services users with ASD. These include:

- Independent Review of Autism Services (Chaired by Lord Maginnis of Drumglass – 2007);
- Autistic Spectrum Disorder Strategic Action Plan 2009;
- Autism Act 2011;
- Department of Health, Social Services and Public Safety (DHSSPS) Autism Strategy and Action Plan Draft 2012.

1.2 The Purpose of the Document

The purpose of this document is to outline the range of support which may be provided to children, young people and adults with autism and their families or carers. The guidance should be read alongside the Children’s Care Pathway entitled ‘Six Steps of Autism Care’, which provides guidance on Autism Spectrum Disorder (ASD), and covers the identification and diagnosis of ASD, and access to interventions and services for children and young people with ASD. The guidance should also be read in conjunction with the Adult Care Pathway which outlines the development of a standardised pathway for the specialist assessment of adults presenting with possible ASD.

This guidance is intended for use by service users, parents, carers, health care professionals, primary care practitioners, education professionals, careers advisers, social security officers, voluntary organisations, employers and any others who offer guidance to or are working with adults with autism.

Section 2 outlines the context for support needs of children and young people and their families and section 3 focuses on adults with ASD and their carers.

2.0 Family Support for Children, Young People and their Families

This guidance incorporates local and regional considerations, and reflects many principles as noted within the following publications:

- Office of the First Minister and Deputy First Minister Strategy for Children and Young People – ‘Our Children and Young People – Our Pledge – A 10 Year Strategy
- The United Nations Convention on the Rights of the Children (UNCRC)
- The United Nations Convention on the Rights of Persons with a Disability
- DHSSPS (2007) Care Matters Northern Ireland (NI)
- Children (NI) Order 1995
- DHSSPS (2011) Understanding the Needs of Children in NI (UNOCINI) Guidance
- DHSSPS (2009) Families Matter: Supporting Families in NI
- DHSSPS (2006) Caring for Carers – A Carers Strategy NI
- The Carers and Direct Payments Act NI 2002

2.1 The DHSSPS strategic policy in NI - is driven by the need to enable parents to support their children and to build communities in which parents can access the support they require. There a range of strategy documents which set out a common vision.

Families Matter 2009 defines family support as *“the provision of a range of supports and services to ensure that all children and young people are given the opportunity to develop to their full potential. It aims to promote their development primarily by supporting and empowering families and strengthening communities. Its focus is on early intervention, ensuring that appropriate assistance is available to families at the earliest opportunity at all levels of need.”*

2.2 The Family Support Model initially developed by Pauline Hardiker, is used to map and understand the range of family support services. It enables a ‘whole system’ approach to service planning to be conceptualised and emphasises the important links between the different levels of provision. Further, it is important that adequate service provision exists at all levels of the family support continuum. The most vulnerable children and families need to be supported in making the best use of the universal services that exist for all families. Many children and young people can be vulnerable at particular points of their development and will need the support of preventative services to ensure that more enduring problems are not allowed to occur.

The Hardiker model has been adapted to show need and services below. The levels of services are described as follows:

- **Level 1:** this represents services for the whole population, such as mainstream health care, education and leisure facilities.
- **Level 2:** this represents support for children who are vulnerable, through an assessment of need and are targeted through specific services.
- **Level 3:** this represents support to families, or individual children and young people, where there are chronic or serious problems, provided through a complex mix of services across both the statutory and voluntary/community sectors.

- **Level 4:** this represents support to families, or individual children and young people, where the family has broken down temporarily or permanently, levels 1-3 services having not met their needs.

2.3 High Level Outcomes are outlined in Families Matter as follows:-

Being healthy – Enjoying good physical and mental health and living a healthy lifestyle free of alcohol and drug abuse, with access to the services to maintain such a lifestyle. Families should be able to develop the confidence and capabilities to love and protect their family members.

Keeping safe – Being protected from harm and neglect; living without fear. Children and their families should be able to live in safe, secure communities, provided with the skills and knowledge to protect themselves from abuse, harassment, discrimination, prejudice, exploitation and neglect.

Enjoying, learning and achieving – Getting the most out of life and obtaining the skills and confidence to realise their potential. Children and young people should be supported to achieve their educational potential by supporting their families and affording them access to both universal and specialist services in times of need.

Making a positive contribution – Add value to the community and society by not engaging in anti-social or offending behaviour. Supported by multidisciplinary and cross-organisational working within the community.

Economic well-being – Having the ability to do the things that you want to, to give you fulfillment and enjoyment, with enough money and the prospects to do well in life. Financial support to help families in times of crisis.

Enjoy your rights – Everyone has the right to be free from the things that harm them. Everyone should expect those with a duty of care towards them to uphold the laws that are there to protect the public. Violation of the rights of children and their families should not be tolerated and any failure to do so should be dealt with appropriately.

2.4 Understanding the Needs of Children in Northern Ireland (UNOCINI)

The UNOCINI framework has been developed and implemented through the Reform Implementation Team, DHSSPS as the agreed model for the assessment, planning and delivery of services to children in need within Northern Ireland and across all the core agencies involved with children and their carers. The UNOCINI guide is important for the following reasons:-

- UNOCINI can help to identify the needs of the child.
- UNOCINI can be used to communicate these needs clearly and concisely to professional colleagues, including those from outside your organisation.
- UNOCINI can assist in getting other services to help, because they will recognise that a concern is based on evidence.

3.0 Support for Adults with ASD/Autism and their Families

The key strategic drivers for support in relation to adults with autism and their families include:

- DHSSPS Bamford Review of Mental Health and Learning Disability (NI) 2007;
- DHSSPS The Service Framework for Mental Health and Wellbeing 2011;
- DHSSPS The Learning Disability Service Framework 2012;
- DHSSPS Caring for Carers – A Carers’ Strategy NI 2006;
- The Carers and Direct Payments Act NI 2002.

3.1 The Bamford Review provides the strategic backdrop for the development of support services for adults with Autism.

“From its outset, the Bamford Review of Mental Health and Learning Disability (NI) has been conscious that people with ASD have a wide variety of needs, some of which are met within learning disability services, some within mental health services and some within other programmes and some needs not met at all”.

A key recommendation is that service provision for ASD must embrace partnership approaches that integrate and provide a whole systems approach. Key areas were identified for service development including assessment and diagnosis; Intervention; individual and family support; training and management and co-ordination.

3.2 Support to Individuals and their Families

Individuals with autism often require support across a range of areas including education and training; employment; housing and benefits. This requires effective interagency working across a range of statutory and third sector organisations.

Information on support services should be made available to each individual with autism and to their carers. Discussion about support should be carried out in partnership with the individual and their families (where relevant) through a process of a two-way engagement. Support should be incorporated into the individual’s Person Centred Plan and should set out the key elements required to meet the support needs of the individual.

3.3 Involving Families and Carers

An individual who has autism should be asked if and how they want their families or carers to be involved in their care. If the person with autism wants their family or carer(s) to be involved, this should be supported; and issues of confidentiality and sharing of information should be explored. It is important to explain how families or carers can help support the person with autism and help with intervention and support plans, when needed to do so.

If a person with autism does not want their family or carer(s) to be involved in their care, the family or carers should be given verbal and written information about autism, and advised about who they can contact if they are concerned about the person's care and support.

3.4 Definition of a Carer

As identified in the DHSSPS (2006) Strategy Caring for Carers, “*Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people (young carers) who care for another family member.*”

The Northern Ireland Single Assessment Tool provides a Carer’s Support and Needs Assessment to be used to facilitate an independent assessment for the carer in his/her own right. The Carers and Direct Payments Act (NI) 2002. Carer’s Assessment and Information Guidance places a requirement on Health and Social Care (HSC) Trusts to inform carers (including young carers) of their right to a carer’s assessment and gives HSC Trusts the power to supply services directly to carers to help the carer in their caring role.

Each HSC Trust has a **Carer Co-ordinator** who will be a point of contact for carers and keep a register of carers. In addition they may:-

- organises carer events;
- provides application forms for carer support grants;
- holds a carers’ register;
- provides an extra care family training programme;
- run young carers’ groups; and
- run carers’ support groups.

4.0 A Support Model for ASD

Meeting the support needs of individuals, families and carers should be carried out in partnership with families through a process of two way engagement and is critical at the point of referral to specialist service, diagnosis, post-diagnosis and at times of transition. This does not preclude the need for longer term support for families due to the demands placed on them in their role as carers, in particular, during their child’s development and early adulthood. *Eligibility criteria must not exclude children, young people or adults on grounds of IQ and intervention must be determinate on assessment and needs-led.*

All assessments must consider the whole child model and person-centred approach and ensure that, in addition, the needs of siblings and carers are clearly addressed as appropriate. The need to provide intervention for siblings is well researched. Siblings often take on roles of young carers and responsibilities beyond their years.

4.1 Core Elements of a Support Model

The key support requirements for children, young people, adults and their families will be needs-led, and follow a tiered approach as appropriate to their needs at any given time. Needs may change over time and the levels of support required may also change. Levels of need are defined by the Hardiker model on page 3 and 4 of this document.

Examples of Services across the 4 Levels (Hardiker’s model) are described in the following table:

Level 1	Level 2	Level 3	Level 4
Provision of accurate verbal and written information and signposting	Support/counselling at the time of diagnosis	Short breaks	Residential Care options
Consideration given to how diagnosis is shared: practical support such as transport and crèche facilities	Behavioural support to understand and manage children, young people or adult with ASD	Befriender/advocate	Supported accommodation options
Early intervention and parent /carer skills programmes including programmes specific to child/young person/adult	Social skills support	Direct Payments, where appropriate	Emergency out of hours support from social work or Urgent Care (medical)
Practical support/advice regarding legislation, education, welfare benefits, housing employment	Social groups	Support to live independently	
Healthcare support, including immunisation, health promotion work.	Listening Ear Service –	Assistance in finding appropriate employment opportunities	
Access to leisure and meaningful activity tailored to needs and interests	Peer support groups	Access to carer support and respite	
Provision of educational and support services			

Please note the support elements may vary and change over time and depending upon the age of the child, young person or adult with ASD. Please also note this is not a definitive list of support services and may each Trust will have their own range of services.

5.0 Core Principles of Support Planning

The following principles have been taken from the Northern Ireland Children's Services Plan (2008-11) and are applicable to adults as well as children. They form the foundation of support provided across NI:

1. Working in partnership is an integral part of supporting families. Partnership includes children and young people, adults, families, professionals and communities.
2. Support interventions are needs-led and strive for the minimum intervention required.
3. A clear focus on the wishes, feelings, safety and well-being of children/adults is maintained.
4. Services are based on a strengths based perspective which is mindful of resilience as a characteristic of many children and families' lives.
5. Support services strengthen informal support networks and should be accessible and flexible in respect of location, timing, setting and changing needs.
6. Services aim to promote social inclusion and equality, addressing issues around ethnicity, disability and rural/urban communities.
7. The participation of service users and providers in the planning, delivery and evaluation of family support services is promoted on an ongoing basis.

5.1 Support Plan

Individuals, families and carers will, as part of the assessment, diagnosis and interventions processes, be offered on-going support according to their needs.

Particular attention must be given to supporting the individual and their family during 'transition' times, for example, school transition points, moving away from the parental home.

The Support Plan can be incorporated into the tailored Intervention Care Plan, as required, and will set out the key elements required to meet the support needs of the child, young person, and adult with ASD, and their families or carers.

The support plan should involve all relevant multi-agency colleagues including education, careers advisors, voluntary sector, and others as appropriate. The intervention should be individualised and tailored to meet the requirements of the individual and their family or carers. The plan should be developed using a person-centred planning approach and working in partnership with all parties. The plan should identify a named contact for ongoing assistance, as required (or based on assessed need).

5.2 Elements of the Support Plan

- The findings from the multidisciplinary assessment and diagnostic process;
- The type and level of support that the person with autism needs including therapy and other interventions;
- Carers (including young carers) Assessment;
- Respite, Short Breaks, where appropriate;
- Information about:-
 - Autism and co-existing conditions;
 - Available parent skills programme opportunities which need to be age-specific;

- Potential educational approaches;
- Entitlement to benefits including Disability living allowance, support from the Family Fund;
- Guide to Direct Payments;
- Further education, supported housing and employment;
- Potential voluntary/community supports;
- Recommended sources of further information.
- When and how often the client's support and care will be reviewed.

5.3 Support Options May Include:

- Advocacy;
- Condition-specific information;
- Communication strategies;
- Education based interventions;
- Environmental adaptations and sensory processing strategies;
- Family support programme;
- Finance and Benefits signposting;
- Mental health and well-being promotion based on recovery;
- Support for co-occurring conditions;
- Psychological and behavioural support programmes;
- Personalisation/self-directed support;
- Support to live independently in the community;
- Suitable housing;
- Voluntary and community sector involvement;
- Training and employment support.

It is essential to acknowledge the significant contribution made by the voluntary and community sector organisations, who provide a range of supports to children and young people, adults with autism, families and carers, for example, helplines, newsletters, skill development workshops, support groups, befrienders, advocates, summer schemes and supported living options.

5.4 Review and Ongoing Support

Once the Support Plan is set up, the named contact person/keyworker within the HSC Trust will facilitate reviews with the individual and their carer(s), as required and remain a central point of contact for future enquiries or concerns.

The guiding principles of the Review process are to:

- Involve the child, young person or adult with autism;
- Involve the parents or carer(s);
- Involve service providers/other agency staff as appropriate;
- Share information on progress towards identified goals and support needs;
- Review the Person Centred Care Plan and services, together with the level of the individual's needs and risks;
- Arrange/facilitate appropriate interventions as required;
- Individuals with autism often require support across a range of areas including; education and training, employment, housing and benefits. This requires effective

interagency working across a range of statutory and third sector organisations.

REFERENCES

Hardiker, P. & Baker, M. (1995) The Social Policy Contexts of Child Care London: NSPCC

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OFMDFM [Office of the First Minister and Deputy First Minister] (2006) Our children and young people: our pledge: a ten year strategy for children and young people in Northern Ireland 2006–2016

New Zealand Autistic Spectrum Disorder Guide, 2008

<http://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline>

Health and Social Care Board: Six Steps of Autism Care for Children and Young People in Northern Ireland 2010

Health and Social Care Board: Autism Adult Care Pathway – 2012

<http://www.hscboard.hscni.net/asdnetwork/Publications>

The NHS Map of Medicine – Diagnosis and Management of ASD

www.nhs.uk/Conditions/Autistic.Spectrum Disorder./Pages/MapofMedicinepage

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APPENDICES

Appendix 1 – Examples of Age Specific Support Elements

Appendix 2 – Support Continuum Diagram

Appendix 1 - Examples of Age Specific Support Elements

Support for Children

- Work in partnership with Social Services and Education;
- Access to carer support and respite;
- Managing challenging behaviour – training and ongoing support;
- Reliable and regular access to information;
- Occupational Therapy/Speech Language Therapy;
- On call service;
- Direct Payments;
- ASD Buddy/mentor;
- Short breaks;
- Afterschools provision;
- Social play opportunities – 1-2-1;
- Support groups.

Support for Young People

- Social skills training;
- Child & Adolescent Mental Health Service (CAMHS) support – to parents;
- Age appropriate respite;
- Transitions worker – health and education;
- Befriender/advocate;
- Safe community services provision;
- Workshops for teenagers;
- Programmes to develop self-esteem;
- Short Breaks;
- Parenting skills programmes (new diagnosis/adolescence).

Support for Adults

- Access to social groups developed with their participation and tailored to their needs, including social skills;
- Further and higher education;
- Assistance in finding appropriate employment opportunities. The Disability Discrimination Act now requires employers to make 'reasonable adjustments' to reduce and remove a substantial disadvantage to a disabled employee or job applicant;
- Mental health support;
- Life coach;
- Short breaks;
- Financial advice and State Benefits information;
- Opportunities to access mainstream leisure activities;
- Out of hours support available in an emergency from the emergency social work service or urgent care services available in each area.

Appendix 2 - Examples of Core Elements of Support

Care Pathway Continuum

