



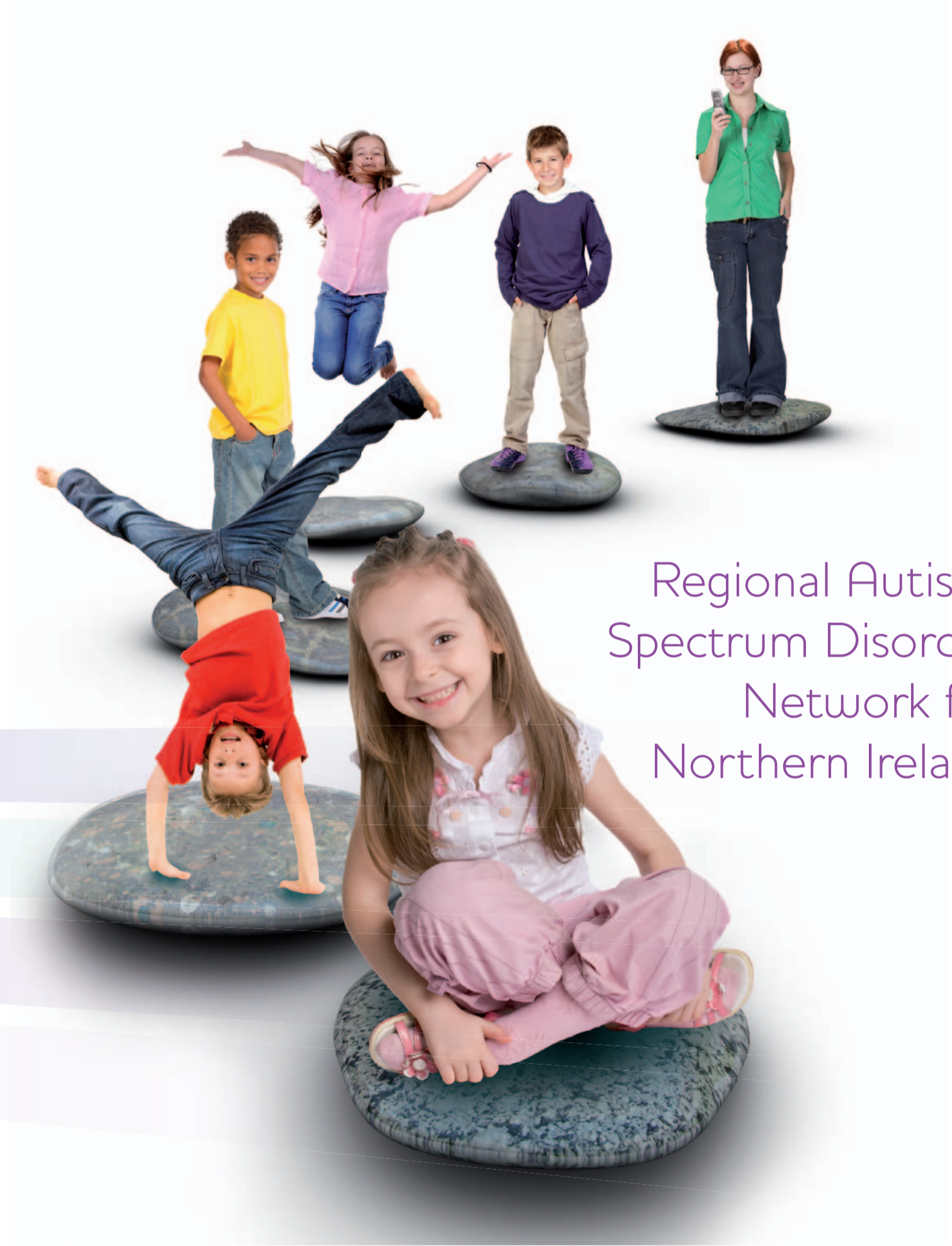
### Acknowledgments

The Regional Autism Spectrum Disorder Network would like to thank the many individuals involved in the development of this Guide. In particular, a special word of thanks to the members of the Regional Reference Group, parents, carers and service users, who have shared their lived experience of autism in support of this publication. This has been greatly appreciated.

### Alternative Formats

This Guide can also be made available in alternative formats: large print, computer disk, Braille, audio tape or translation for anyone not fluent in English. Contact the Communications Office at the Health and Social Care Board [www.hscboard.hscni.net](http://www.hscboard.hscni.net).

# Autism: A Guide for Families



Regional Autistic  
Spectrum Disorder  
Network for  
Northern Ireland

We created this Guide to provide written support to you following the diagnosis of Autistic Spectrum Disorder\* (ASD) for your child or young person.

Our aim is to provide accurate, useful and unbiased information about ASD. We hope that this resource will help you to understand more about these conditions, and guide you through the services you may need to access.

ASD is a spectrum disorder which means that it affects each person differently. Some individuals will need support only at specific times in their life; others may need ongoing support.

Following diagnosis of an ASD, you may feel a sense of relief that you have an explanation for the many things which have concerned you. You may feel overwhelmed and confused. You may also feel worried about the future. We want to reassure you that you are not alone, and that there are many other parents and families here in Northern Ireland who have a child(ren) or a young person(s) with ASD.

In this Guide you will find details of the Health and Social Care Board's 'Six Steps of Autism Care' document. This document shows how services and support will adapt to meet both you and your child or young person's changing needs over the coming years. It will direct you through assessment, diagnosis, treatments/interventions, family support, education and much more.

Your ASD Co-ordinator within your local Health and Social Care Trust can provide you with a list of ASD services, information on local voluntary organisations and other useful resources.

This Guide has been designed to provide you with age-appropriate information, which has been colour-coded in two sections – 'Child' and 'Young Person'. Please do not feel you need to read this Guide all at once, but use it as a signposting resource that you come back to time and again. A Guide for adults with ASD is also being produced.

We hope that this written material will help you to have confidence in your decision-making as a parent/carer. Suggestions are given on how to plan ahead and forge the best future for your child or young person, making it possible for him/her to move towards independence and lead as full a life as possible.

**Dr Stephen Bergin**  
**Chair, Regional Autistic Spectrum Disorder Network (RASDN)**

October 2011

(\*The term ASD refers to all diagnoses on the autism spectrum, including autism and Asperger's Syndrome.)



## Regional Autistic Spectrum Disorder Network (RASDN)

This multi-disciplinary and multi-agency collaboration includes service users, parents and carers. It was set up in June 2009 and is managed by the Health and Social Care Board. RASDN aims to improve outcomes for individuals who have an Autistic Spectrum Disorder (ASD), and their families.

Log on to [www.hscboard.hscni.net](http://www.hscboard.hscni.net) for further details about RASDN.

### RASDN Members:

Department of Health, Social Services and Public Safety	<a href="http://www.dhsspsni.gov.uk">www.dhsspsni.gov.uk</a>
Health and Social Care Board	<a href="http://www.hscboard.hscni.net">www.hscboard.hscni.net</a>
Public Health Agency	<a href="http://www.publichealth.hscni.net">www.publichealth.hscni.net</a>
Belfast Health and Social Care Trust	<a href="http://www.belfasttrust.hscni.net">www.belfasttrust.hscni.net</a>
Northern Health and Social Care Trust	<a href="http://www.northerntrust.hscni.net">www.northerntrust.hscni.net</a>
Southern Health and Social Care Trust	<a href="http://www.southerntrust.hscni.net">www.southerntrust.hscni.net</a>
South Eastern Health and Social Care Trust	<a href="http://www.setrust.hscni.net">www.setrust.hscni.net</a>
Western Health and Social Care Trust	<a href="http://www.westerntrust.hscni.net">www.westerntrust.hscni.net</a>
Department of Education	<a href="http://www.deni.gov.uk">www.deni.gov.uk</a>
Department for Employment and Learning	<a href="http://www.delni.gov.uk">www.delni.gov.uk</a>
Education and Library Boards	Belfast: <a href="http://www.belb.org.uk">www.belb.org.uk</a> North Eastern: <a href="http://www.neelb.org.uk">www.neelb.org.uk</a> South Eastern: <a href="http://www.seelb.org.uk">www.seelb.org.uk</a> Southern: <a href="http://www.selb.org/home.htm">www.selb.org/home.htm</a> Western: <a href="http://www.welbni.org">www.welbni.org</a>
Reference Group: Parents, Carers and Service Users	
Action for Children	<a href="http://www.actionforchildren.org.uk">www.actionforchildren.org.uk</a>
Autism Initiatives Northern Ireland	<a href="http://www.ai-ni.co.uk">www.ai-ni.co.uk</a>
Autism Northern Ireland	<a href="http://www.autismni.org">www.autismni.org</a>
Autism Network Northern Ireland	<a href="http://www.autismnetworkni.org.uk">www.autismnetworkni.org.uk</a>
Barnardo's	<a href="http://www.barnardos.org.uk">www.barnardos.org.uk</a>
EAGLE	<a href="http://www.belfastcentralmission.org">www.belfastcentralmission.org</a>
Mencap	<a href="http://www.mencap.org.uk">www.mencap.org.uk</a>
Parents' Education as Autism Therapists (PEAT)	<a href="http://www.peatni.org">www.peatni.org</a>
Special Provision for the Education of Autistic Children (SPEAC)	<a href="http://www.speac-centre.org">www.speac-centre.org</a>
The National Autistic Society	<a href="http://www.autism.org.uk">www.autism.org.uk</a>

## What Is Autistic Spectrum Disorder (ASD)?

Diagnosis of ASD is based on the observation of impairments in behaviour, communication and social interaction. Currently, there is no known medical test to diagnose this condition.

We do know that it is not:      a learning disability;  
   a mental health problem; or  
   due to poor parenting.

It is, however, a neurological and developmental condition. It affects individuals from all walks of life, ethnicity and socio-economic backgrounds.

### What are the symptoms of ASD?

Symptoms typically start sometime in the first three years of life. They usually develop from birth (about 4 in 5 cases). However, in about 1 in 5 cases there is a period of normal development first before symptoms begin. Some children with ASD may not seem to have any symptoms until later on, even after they have started school.

The symptoms of ASD vary between individuals. Some people have minimal symptoms whereas others many have severe difficulties. People with ASD have varying levels of intelligence - some have very high IQs.

There are four different groups of symptoms, all of which usually occur in children with ASD.

#### 1. Social difficulties

There are different types of problems and not all will occur in each case. These can generally be described as 'not being able to get on with people'.

So the child may:

- Seem to be distant;
- Have little or no interest in other people;
- Have no real friends;
- Not understand other people's emotions;
- Prefer being alone;
- Have problems with language and communication.



## 2. Speech

Speech usually develops later than usual. When it does, the language (the use and choice of words) may develop wrongly. The sort of problems that children/young persons with ASD may have, include one or more of the following:

- Not being able to express themselves well;
- Not being able to understand gestures, facial expressions, or tone of voice;
- Saying odd things. For example, repeating your words back to you, time and time again;
- Using odd phrases and odd choices of words;
- Sometimes using many words when one would do;
- Making up their own words;
- Not using their hands to make gestures as they speak;
- Not being able to understand difficult commands.

## 3. Poor imagination

Typically, imaginative play is limited in children with ASD. They tend to do the games and activities that they learn over and over again. Games may remain exactly the same every day. Games are usually those that a younger child would normally play.

## 4. Unusual behaviours

These include one or more of the following:


- Mannerisms such as hand-flapping;
- Anger or aggression if routines are changed;
- Actions may be repeated over and over again.

## Sensory over-arousal and under-arousal

Most individuals with ASD have sensory sensitivities (over and/or under sensitive to sound, sight, taste, smell and touch) which may make it difficult for them to process information in the same way as others.

## Further information

- What is ASD?:  
[www.nhs.uk/conditions/autistic-spectrum-disorder/pages/introduction.aspx](http://www.nhs.uk/conditions/autistic-spectrum-disorder/pages/introduction.aspx)
- What is ASD?:  
[www.patient.co.uk/health/autism.htm](http://www.patient.co.uk/health/autism.htm).



*“You are not on your own. You know your child best.”*

(Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

## Further information

- Department of Health, Social Services and Public Safety, Autism Spectrum Disorder Action Plan (2009):  
[www.dhsspsni.gov.uk/asd\\_strategic\\_action\\_plan\\_-\\_easy\\_read\\_format.pdf](http://www.dhsspsni.gov.uk/asd_strategic_action_plan_-_easy_read_format.pdf)
- Health and Social Care Board:  
[www.hscboard.hscni.net](http://www.hscboard.hscni.net)
- Belfast Health and Social Care Trust:  
[www.Belfasttrust.hscni.net](http://www.Belfasttrust.hscni.net)
- Northern Health and Social Care Trust:  
[www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)
- South Eastern Health and Social Care Trust:  
[www.setrust.hscni.net](http://www.setrust.hscni.net)
- Southern Health and Social Care Trust:  
[www.southerntrust.hscni.net](http://www.southerntrust.hscni.net)
- Western Health and Social Care Trust:  
[www.westerntrust.hscni.net](http://www.westerntrust.hscni.net)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

## ASD Diagnosis: What To Expect

### ASD Diagnosis: What To Expect

As a parent/carer you may have concerns about your child/young person's development or whether he/she may have ASD. The first person you should approach will be your GP, health visitor or school teacher, depending upon the age of your child/young person.

The following information guides you through the journey ahead about raising your initial concerns, through to a professional telling you that your child/young person may have ASD, or not. This process is called the 'Six Steps of Autism Care' and it has been designed by the Health and Social Care Board in partnership with Health and Social Care Trusts, Public Health Agency, Department of Education, Education and Library Boards, voluntary organisations, and most importantly parents/carers and service users.

#### What is the 'Six Steps of Autism Care'?

The 'Six Steps of Autism Care' document tells you about the journey your child/young person, and you, will take through the assessment process, diagnosis and follow-up support. It will give you information about each step in the process, about who will see your child/young person, what tests will take place, and tell you whether your child/young person has ASD or not.

#### How can the 'Six Steps of Autism Care' help my child/young person?

The 'Six Steps of Autism Care' aims to make the process as clear and responsive as possible, for your child/young person, and you. It will ensure you get the right information, at the right time from the right people. It will help you to understand the roles of the individuals who will carry out their assessments, so you know how and why the final decision is made.

#### How does the 'Six Steps of Autism Care' start?

Once your GP, health visitor, or other professional with whom you are in contact is sure that your child/young person is experiencing difficulties, they will refer him/her for an assessment. This can be



a referral to a paediatrician, which will be an outpatient appointment at either hospital or child development clinic in a health and care centre, or by any other professional working in either in health or education. To start the referral process they will have to complete a standardised Autism Service Team referral form, which will be completed by them, but will seek information from you.

### What happens next?

**Step One:** A referral is made by an appropriate professional to the specialist Autism Service Team in your local Health and Social Care Trust.

**Step Two:** You will be contacted by a member of the Autism Service Team within four weeks of this referral with details about your appointment, if the referral has been accepted for assessment. At this time the Autism Service Team will also seek information from any services your child/young person is currently receiving.

**Step Three:** One or more meetings will take place to carry out some tests with your child/young person. This is called the assessment process and this can happen at home, at school, or at the Autism Clinic. This will commence within 13 weeks from the referral made to the Autism Service Team. This process can take a number of weeks to complete.

**Step Four:** Once the ASD assessment has taken place, you will either be informed on that occasion or at a later meeting, on an agreed date, of the outcomes of the assessment (tests) and be advised if your child/young person has ASD or not, and what will happen next.

**Step Five:** Staff will talk to you about the treatments/interventions to be put in place for your child/young person. These treatments/interventions are known as the tailored Intervention Care Plan and will be based on your child/young person's assessed needs. They will commence within 13 weeks of getting your child/young person's diagnosis. Ongoing family support will also be made available.

**Step Six:** When the initial agreed treatments/interventions have been completed, usually taking up to one year, you will be contacted by the Autism Service Team, to come for a review appointment to check on your child/young person's progress. You will be advised of a named worker to support you throughout this period and you may seek advice at any time.

*“Your child is the same person they were yesterday.”*

(Parent/Carer)

### Who does the assessment?

The team involved in making the ASD diagnosis will be multi-disciplinary, comprising at least two members from the following:

- paediatrician;
- child psychiatrist;
- speech and language therapist;
- occupational therapist;
- clinical psychologist;
- specialist health visitor;
- mental health practitioner - Child and Adolescent Mental Health Services (CAMHS);
- social worker;
- specialist nurse;
- educational psychologist;
- other trained professionals with relevant knowledge and expertise.

All professionals who carry out assessments for ASD, in addition to their professional qualifications, will have expertise acquired through ASD-specific and related conditions training, professional development, supervision and work experience.

### What happens after diagnosis?

After diagnosis, you will be given a written copy of the assessment process. This should be written in such a way that you understand what is being said and have a clear understanding of the agreed care plan that is being developed, and put in place in partnership with you, for your child/young person and your family. You will know the following:-

- all who will be working with your child/young person and you;
- which treatments/interventions they will be offering and why;
- what support will be available to you and information about agencies who can help;
- a named person to whom you can direct queries, during or after this initial treatment/intervention process, has been completed.

To view the full version of the 'Six Steps of Autism Care' document log on to the Health and Social Care Board's website.



## Your New Caring Role

For most parents/carers, it is not easy to discover that your child/young person has ASD. Following the diagnosis it is usual to experience a range of emotions. Some parents/carers may feel shock and disbelief, or denial and anger, others may experience confusion and fear.

You may find the suggestions below will help you to use these emotions in a more positive way. Emotions are experienced in different orders, and at different stages of life.

- Disbelief - Make a list of questions to ask, talk to close family and friends.
- Denial - Gather information and learn more about autism.
- Anger - Refocus your anger to become a better carer for your child/young person.
- Depression - Take time out, and do something that you really enjoy. Speak to a family member, friend, GP or therapist.
- Guilt - It is not your fault - nothing you did or did not do was a contributory factor to your child/young person's ASD.
- Hope - Your child/young person will surprise you. Celebrate and share all achievements.
- Acceptance - Accepting the diagnosis simply means that you have worked through the above emotions, and have gained a new perspective on living with disability, and are now ready to advocate for your child/young person.

Helping your child/young person to develop is what being a parent/carer is all about. The strongest influence in a child/young person's life is made by his/her parent(s)/carer(s). Your efforts will make a huge difference in his/her life.

Sometimes making things better for your child/young person with ASD can happen at the expense of your own health and well-being. You must take care of yourself to be able to take care of your child/young person and your family. Ask for help. As one individual, you cannot be expected to meet all of the needs of your child/young person. Asking for help is a positive first step, which allows you to find out about the resources and support services available to you and your family.



Maintaining a life outside of ASD is important for your own personal development and psychological well-being. You may find your social networks become considerably reduced but equally, you may make new friends, some of whom have children/young persons with ASD themselves. Joining support groups and online communities is one way of learning together through sharing of experiences.

### Carer's Allowance

If your child/young person is in receipt of the higher or middle rate of Disability Living Allowance (DLA), you may be entitled to Carer's Allowance. This benefit is different to the Carer's Assessment which is carried out by your local Health and Social Care Trust. Further information on DLA can be viewed on the 'Financial Support and Benefits' section of this Guide.


### Further information

#### Northern Ireland Direct

- An Overview of Carers' Rights: [www.nidirect.gov.uk/index/information-and-services/caring-for-someone/carers-rights/an-overview-of-carers-rights.htm](http://www.nidirect.gov.uk/index/information-and-services/caring-for-someone/carers-rights/an-overview-of-carers-rights.htm)
- Carer's Allowance: [www.nidirect.gov.uk/carersallowance](http://www.nidirect.gov.uk/carersallowance)
- Special Education Needs in Under Fives: [www.nidirect.gov.uk/index/information-and-services/parents/preschool-development-and-learning/special-educational-needs-in-under-fives.htm](http://www.nidirect.gov.uk/index/information-and-services/parents/preschool-development-and-learning/special-educational-needs-in-under-fives.htm)

#### Other sources

- Information for Carers: [www.direct.gov.uk/en/CaringForSomeone/DG\\_071391](http://www.direct.gov.uk/en/CaringForSomeone/DG_071391)
- Family Support Northern Ireland: [www.familysupportni.gov.uk](http://www.familysupportni.gov.uk)



*“What is important is that as a parent/carer you make sure paths are open to them, support them, advocate for them. What they give in return is incredible.”*

(Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## ASD and Your Family

### Supporting each other

It is important that family members, not only support each other, but also seek help from the wider family circle and friends, especially so if you are a lone parent.

Developing a strong relationship with your partner is also important. You can do this by making sure that both of you have regular breaks together, away from your parenting/ caring roles.

For many parents/carers who work, outside the home, their time at work is a break from their caring responsibilities. Your child/young person's needs may however require you to reduce your hours at work, or even give up work. You may find that you will have less free time for yourself, and for other members of your family. It is important nonetheless to endeavour to make time and space for all your family members.

### Siblings

Each family member is affected in different ways when a child/young person has a diagnosis of ASD, especially their brothers/sisters.

It is beneficial for the needs of your entire family to be balanced. Make an effort to give full attention to all of your children, not just your child/young person with ASD.

What matters most is that your children are growing and maturing at a rate that is appropriate for them. Your child/young person with ASD may need additional help, but as all your children grow, you need to keep the changing needs of your entire family in mind. It is very easy to become totally focused in helping your child/ young person with ASD to overcome their difficulties, to the exclusion of the needs of your other children. Ask your children what is challenging for them about having a sibling with ASD. Encourage your children to play together and 'bond as a family'.

Siblings may find that they become isolated because of their brother/sister's condition. Just as parents/carers value meeting with other parents/carers and sharing their concerns together, siblings also appreciate meeting others in similar circumstances.

Your children may benefit from attending support groups. Ask your ASD Co-ordinator about activities available in your area, and other resources that siblings could benefit from.



### Extended family

Grandparents are first and foremost parents and will want to help you. Grandparents find the period following diagnosis a difficult time too. Allow them into your life and your child/young person's life. Take up any of their offers of support.

### Further information

- Department of Health, Social Services and Public Safety: Top tips for parents: [www.dhsspsni.gov.uk/public\\_health-toptips](http://www.dhsspsni.gov.uk/public_health-toptips) Quick Link: [bit.ly/nkZJ3o](http://bit.ly/nkZJ3o)
- Northern Ireland Direct: Carer's Allowance: [www.nidirect.gov.uk/carersallowance](http://www.nidirect.gov.uk/carersallowance)


*“My brother’s ASD means I am his best friend and we have lots of fun. He is kind and keeps me right on what is good and what is not.”*

*(Sibling Age 8)*

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

## Further information

- Department of Health, Social Services and Public Safety - Direct Payments: [www.dhsspsni.gov.uk/directpayments-about](http://www.dhsspsni.gov.uk/directpayments-about)
- Family Support Northern Ireland: [www.familysupportni.gov.uk](http://www.familysupportni.gov.uk)



“Support should work with you, and at your pace.”

(Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

## Support For Your Family

## Support For Your Family

### How do I get the help I need?

Meeting the support needs of your family will be carried out in partnership, through a process of two-way engagement. Support is crucial when a family:

- is referred to the Autism Service Team;
- receives a diagnosis for their child/young person;
- requires support after diagnosis; and
- at all times of transition.

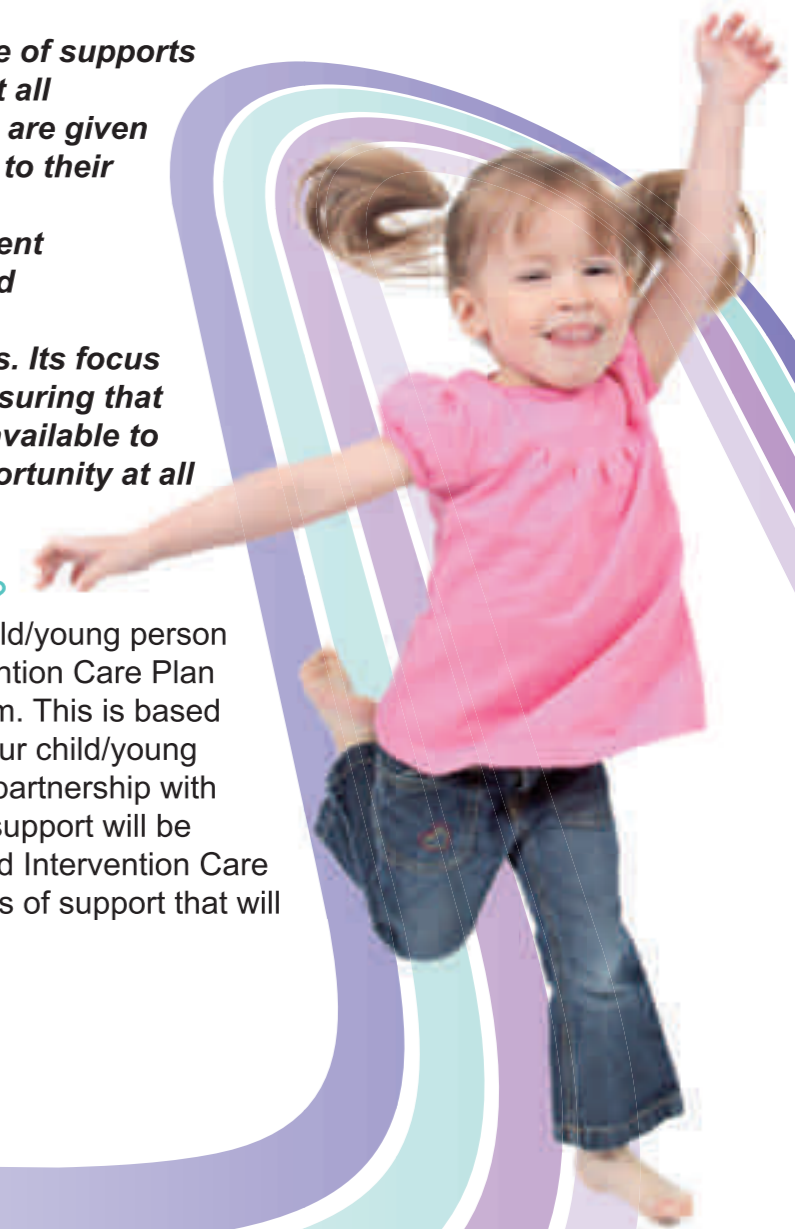
The Department of Health, Social Services and Public Safety's (DHSSPS) strategic policy in Northern Ireland entitled: 'Families Matter', was developed in 2009 to enable parents/carers to support their children/young persons, and to build communities in which parents/carers can access the support they require.

'Families Matter' 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.”***

### What support is available?

Following diagnosis, your child/young person will receive a tailored Intervention Care Plan from the Autism Service Team. This is based on the assessed needs of your child/young person, and is developed in partnership with you and your family. Family support will be incorporated into your tailored Intervention Care Plan and will set out the types of support that will be available.



### You will receive information about the following:

- the conclusions of the multi-disciplinary assessment and diagnostic process;
- the type and level of support that your child/young person requires including treatments/interventions, information and practical advice;
- an explanation of the how, when, where, and whom of professional support that will be provided;
- who will provide home visits for your family and how often they will occur;
- when and how often, your child/young person's support and care will be reviewed;
- when, how and by whom your child/young person's development will be monitored;
- information about the Parent's Guide to Direct Payments, where appropriate, can provide a variety of support services for your family;
- information about Social Security Agency benefits and entitlements;
- planned liaison between your family's named key worker and Department of Education and Department of Education and Learning for your child/young person's educational needs;
- dates for planned reviews/updates to plan/organise how your child/young person's care will change/adapt as he/she grows older.

### Support will:

- result in a Carer's Assessment being offered;
- involve relevant multi-agency colleagues (including; education, social work, voluntary sector and careers' advisors);
- involve working in partnership to tailor treatments/interventions to the requirements of your family based on a person-centred planning approach;
- ensure delivery of services that will meet the needs of your child/young person;
- include discussion about potential educational approaches with you, including additional support for learning, and have in place arrangements for liaising/sharing required information with education services;
- include discussion about wider family/sibling support, provision of respite/short breaks where appropriate, and explain the role of the social work team;

- provide information about:
  - parent skills programmes which are age-specific;
  - recommended sources of further information;
  - your family's named contact for ongoing assistance as required, and based on assessed need.

### Support to your family

The key support requirements for your child/young person and family will be needs-led (observed and assessed concerns). Needs may change over time and levels of support required may also alter. To ensure adequate support, assessment of need will have to be robust and reflective of family circumstances in line with the statutory guidance for health and social care.

### Provision of ongoing family support

ASD may be diagnosed during childhood, adolescence or adulthood. It is a lifelong condition that affects your child/young person's adaptive functioning (daily living skills), from childhood to adulthood to a variable extent, and will require ongoing assessment and treatment/intervention. It is important to ensure that you get access to regular reviews with the Autism Service Team and/or care service, involved with your child/young person and family.

The ASD Co-ordinator in your local Health and Social Care Trust, your GP or voluntary organisations will give you the help that you may need, as well as signpost you to other sources of support.

The Family Support Northern Ireland (NI) website provides details of a wide range of services provided by statutory, voluntary and community organisations. You can access up-to-date information on a range of services available to support families. This information aims to help families, young people and children in Northern Ireland to find local services to meet their needs.



The Disability Discrimination Act (1995) was updated as a result of the Discrimination (Northern Ireland) Order (2006) (DDO). The DDO also put in place additional duties on public authorities when carrying out their functions, to promote positive attitudes and encourage participation by disabled people in public life.

The Northern Ireland Act (1998) is a key piece of equality legislation. It emphasises the positive obligations placed on public authorities in carrying out their various functions relating to Northern Ireland, to have due regard to the need to promote equality of opportunity between nine groups. One of the groups is people with disabilities. This requires the screening and equality impact assessments of policies and decisions.

The Human Rights Act (1998) gives further legal effect to rights contained in the European Convention on Human Rights, including Article 2, the right not to be denied access to education.

\*\*\*\*

All ELBs have the following services:-

Advice and Information Helpline Service: this is to ensure that parents of children with special educational needs can access information and advice in relation to the needs of their children/young people.

Dispute Avoidance and Resolution Service (DARS): this provides an informal forum for exploring differences and for finding a way forward. The process is voluntary and confidential.

#### Further information

##### Department of Education

- Education Guide for Parents: [www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/7-special\\_needs-a\\_guide\\_for\\_parents\\_pg/7-special\\_educational\\_needs\\_-\\_a\\_guide\\_for\\_parents-contents\\_pg.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/7-special_needs-a_guide_for_parents_pg/7-special_educational_needs_-_a_guide_for_parents-contents_pg.htm)
- Special Educational Code of Practice: [www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/special\\_needs-codes\\_of\\_practice\\_pg.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_needs-codes_of_practice_pg.htm)

##### Education and Library Boards

- Belfast Education and Library Board: [www.belb.org.uk](http://www.belb.org.uk)
- North Eastern Education and Library Board: [www.neelb.org.uk](http://www.neelb.org.uk)
- South Eastern Education and Library Board: [www.seelb.org.uk](http://www.seelb.org.uk)
- Southern Education and Library Board: [www.selb.org/home.htm](http://www.selb.org/home.htm)
- Western Education and Library Board: [www.welbni.org](http://www.welbni.org)

##### Equality Commission for Northern Ireland:

- [www.equalityni.org](http://www.equalityni.org)
- Disability Discrimination Act: [www.equalityni.org/sections/default.asp?cms=Your+Rights\\_Disability+discrimination&cmsid=2\\_142&id=142&secid=2](http://www.equalityni.org/sections/default.asp?cms=Your+Rights_Disability+discrimination&cmsid=2_142&id=142&secid=2)

##### Other sources

- Special Educational Needs and Disability Tribunal (SENDIST): [www.education-support.org.uk/parents/special-education/sendist/faqs/](http://www.education-support.org.uk/parents/special-education/sendist/faqs/)

*“Line up all necessary forms of professional support: education, health, social care and respite.”* (Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

## How Best To Meet Your Child/Young Person's Educational Needs

### How Best To Meet Your Child/Young Person's Educational Needs

Your child/young person's special educational needs (SEN) must be met whether they are in nursery, primary or secondary education.

A list of useful questions to help you find the school which can best meet the needs of your child/young person are detailed below:-

- What are the school's policies and procedures with regard to supporting children/young persons with special education needs?
- Does the principal of the school fully support your application to send your child/young person to his or her school?
- Does the Special Educational Needs Co-ordinator (\*SENCO) have knowledge, experience and understanding of ASD and any co-occurring conditions?
- Is there a whole school policy for ASD training?
- Is the school able to adapt the classroom environment to cater for your child/young person's individual needs?
- Is there a specialist ASD service both in health and education which can support your child/young person throughout their education?

\*The SENCO is the teacher in your child/young person's school with responsibility for the day-to-day procedures and provision for SEN. You should talk to him or her about your child/young person if you have any concerns about the support that is provided to them.

#### Getting extra support in school

Providing extra support for your child/young person's SEN is the statutory responsibility of the school and the local Education and Library Board (ELB). There is a Code of Practice that sets out the procedures and stages involved in the process of identifying and assessing Special Educational Needs.

#### Education Plan

An Education Plan (EP) may be provided by your child/young person's teacher if your child/young person has educational needs. The EP is used as a guide to deliver and monitor the achievement of specific goals and objectives.

Your child/young person should have an EP which details the extra support that they will



receive and should address issues such as the development of communication, social skills, literacy and mathematics.

If you believe the current level of provision does not meet your child/young person's educational needs, you may wish to use a more formal process as provided in the Department of Education's Code of Practice.

### Code of Practice

Within the Code of Practice, responsibility for Stages One to Three lies at local school level, and responsibility for Stages Four and Five is shared between your local ELB and the school.

The five stages of the Code of Practice are as follows:

<b>Stage One</b>	Teachers identify and register a child/young person's special educational needs and, consulting the school's SEN co-ordinator, take initial action.
<b>Stage Two</b>	SEN co-ordinator takes lead responsibility for collecting and recording information and for co-ordinating the child/young person's special educational provision, working with the child/young person's teachers. Parents to be informed and involved in any reviews.
<b>Stage Three</b>	Teachers and the SEN co-ordinator are supported by specialists from outside the school.
<b>Stage Four</b>	The ELB considers the need for a statutory assessment and, if appropriate, makes a multi-disciplinary assessment.  This process will gather reports and information from a range of sources (including parents/carers) which will be submitted to the ELB as evidence. Parents/carers have the legal right to request the local ELB to carry out a Statutory Assessment for their child/young person. The ELB will investigate the evidence to support this request and make a decision whether or not to assess the child/young person's needs.
<b>Stage Five</b>	The ELB considers the need for a Statement of Special Educational Needs; if appropriate, it makes a Statement and arranges, monitors and reviews provision.  If a Statement is issued, it will detail how your child/young person's special educational needs will be met. The educational provision outlined in the document is underpinned by statutory legislation.  If a Statement is not issued, you will receive a 'Note in Lieu' which will set out reasons why a Statement is not necessary, and will include all the advice or reports gathered in the Statutory Assessment process.

**(The process of identifying Special Educational Needs is currently under review).**

### Annual Review

If your child/young person has been issued with a 'Statement', an annual review of his/her provision will take place each year. The purpose of this meeting is to check whether the provision and placement, are appropriate to the child/young person's current needs. You will be invited to this meeting which is held in school.

At your child/young person's annual review, the decision will be made to either continue, stop, or amend the Statement.

If your local ELB makes a change to the Statement, they will send you an Amendment Notice. You then have a period of 15 days in which to send them your views, and you can ask to meet them to discuss any concerns you have.

If you agree to the changes, the ELB will then send you and the school an Amended Statement which will have immediate effect.

If you are still not satisfied with the outcome you can lodge a formal appeal to the Special Educational Needs and Disability Tribunal (SENDIST). You have two months in which to lodge your appeal from the date of receipt of the amended Statement.

### For children/young persons who do not have a Statement

1. You should ask to meet the class teacher and the SENCO or Principal to discuss your concerns, outlining the difficulties that your child/young person is having at school, and the support that you feel he/she could benefit from.
2. You should write to the school and Board of Governors outlining the problems that your child/young person is having (noting the dates, times and outcomes of meetings).
3. If there is no change at this stage, you should contact your local ELB's Dispute Avoidance and Resolution Service (DARS).
4. If you are still not happy with the outcome, you can write a letter to the Chief Executive of your local ELB.

### Exclusion from school

Exclusion from school can be permanent or fixed in length. A fixed period of exclusion should not exceed five days at a time, and should be no more than 45 days in a school year. Appeal against expulsion (permanent exclusion) is made to the Expulsion of Pupils' Appeal Tribunal.

### Legislation

Anti-discrimination legislation and associated codes of practice are in place to end discrimination, and ensure reasonable adjustments are made for people with disabilities, within a number of areas including education.

The Special Educational Needs and Disability (Northern Ireland) Order (2005) (SENDO) strengthens the rights of children with special educational needs to be educated in ordinary schools where parents want this and where the interests of other children can be protected.

In relation to disability discrimination, Part III of SENDO points out that a school has a duty not to treat pupils who have a disability less favourably, without justification, for a reason linked to their disability. A school also has a duty to make reasonable adjustments so that pupils who have a disability are not put at a substantial disadvantage, and they have a duty to plan increasing accessibility to their premises and the curriculum.

The Equality Commission for Northern Ireland has produced a Code of Practice in respect of the new disability discrimination duties of both schools and further and higher education institutions.



*“Early input reaps rewards. Make sure you liaise really closely with school - your child/young person is there as many waking hours as he/she is with you.”*

*(Parent/Carer)*



Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

## Appropriate Treatment/Intervention Options For ASD

### Appropriate Treatment/Intervention Options For ASD

After your child/young person has received a diagnosis, suitable treatments/interventions will be discussed with you by a member of the Autism Service Team (AST) within your local Health and Social Care Trust. It is important to note that there is also no single best treatment/intervention for ASD.

The level and type of treatment/intervention offered to your child/young person and you will depend on his/her assessed need. The treatment/intervention programme should be individualised, structured, and family-centred. You, as parent/carers, must be actively involved in this decision making process, especially if extensive programmes which require significant time, energy and commitment are being considered.

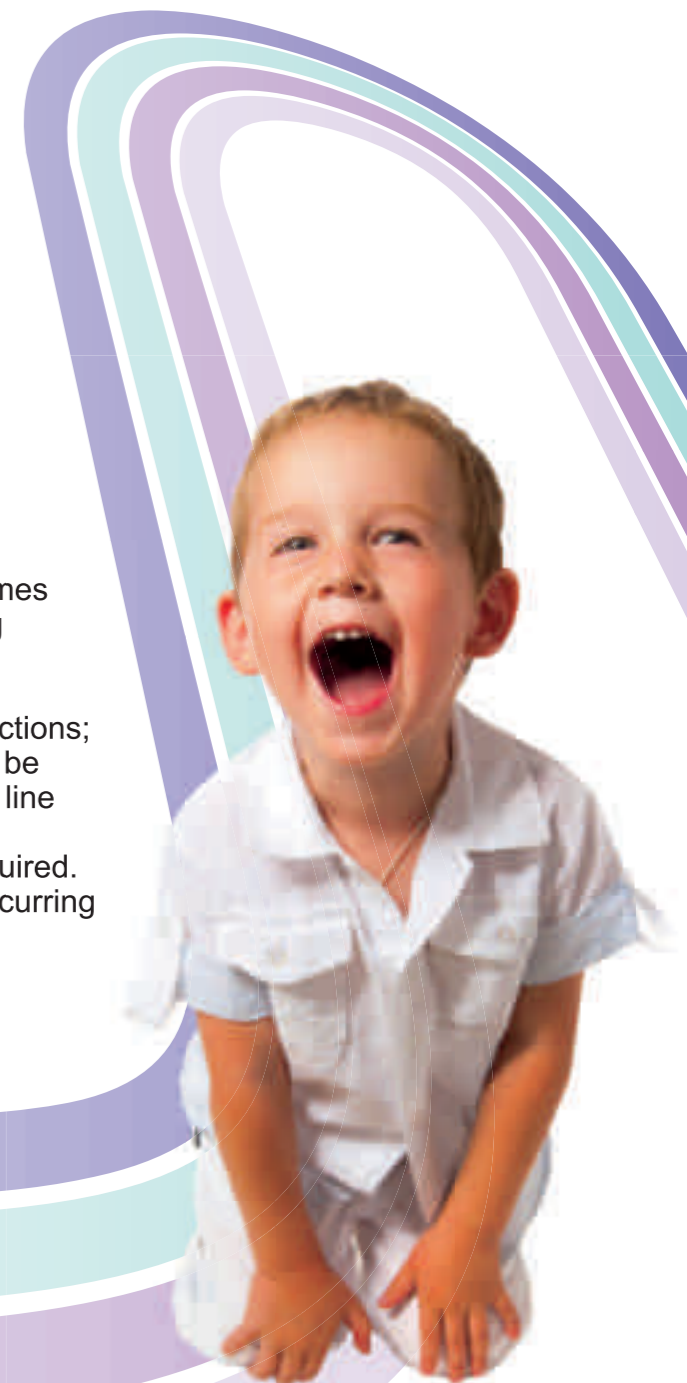
Specialist behavioural and educational treatments have become the main interventions for children/young persons with ASD. Early diagnosis followed by appropriate treatment/interventions can improve outcomes in later life. Tailored and tested treatments/interventions should bring improvements and reduce stress experienced by the whole family.

There are different levels and types of treatments/interventions which include post-diagnostic support for families/carers, training, direct individual and group interventions, access to social activities and respite (short breaks).

The first stage of intervention is a comprehensive assessment and this should be ongoing.

#### Tailored Intervention Care Plan Principles:

1. Child Interventions:
  - Treatment/intervention programmes tailored to meet your child/young person's needs;
  - Addresses the impact of ASD on communication and social interactions;
  - Treatments/interventions should be provided as early as possible, in line with regional guidelines and by appropriate professionals as required.
  - Take account of additional co-occurring conditions or difficulties.



## 2. Family Support:

- Acknowledgement that parents/carers are experts on their own children/young persons, and adequate support is required to enable them to follow ASD-specific programmes;
- Family-centred approaches and daily living programmes should be considered for your child/young person;
- Outcomes of treatments/interventions must meet assessed and expressed needs of families.

## Treatment/interventions along the 'Six Steps of Autism Care'

### Referral Stage

Your child/young person may have been in receipt of services, for example, health visiting or mental health services, and this is likely to continue when he/she is referred to the Autism Service Team at your local Health and Social Care Trust for assessment.

### Diagnostic Stage

When a referral is received by the Autism Service Team, you will receive information on the nature of the assessment process and professionals conducting the assessment.

Health and education professionals must work closely together in all stages of the process of referral, assessment, support, training and identification of appropriate treatments/interventions. A statutory framework exists within the Department of Education for the identification and assessment of special educational needs. (See section on Educational Needs within this Guide for further information).

### Post Diagnostic Stage

The needs of your child/young person will change over time, depending on their developmental and life stage and the necessary supports will vary accordingly. Health and social care staff, in partnership with family parents/carers, education providers and other agencies, will seek to address the needs of the child/young person as part of an integrated tailored Intervention Care Plan. Local Health and Social Care Trusts, through their Autism Service Teams, will ensure all treatment/interventions are co-ordinated and organised into a single care pathway process.

At a post diagnostic meeting, which addresses your child/young person's needs and identifies priorities for treatment/intervention, a tailored Intervention Care Plan will be drawn up in partnership with you and your family. This will ensure that you do not have to navigate your way around different treatment/intervention services. Joined up working within and between programmes of care, for example, social work and Child and Adolescent Mental Health Services (CAMHS), is also essential when required.

Treatments/interventions that your child/young person and family can expect are:

1. **ASD information sessions** (for parents/carers, families and individuals). Sessions should focus on enhancing parent/carer knowledge of ASD, empower parents/carers to use this knowledge to promote your child/young person's development and use strategies beneficial to your child/young person.
2. **Family support** - Meeting the support needs of your child/young person and family should be carried out in partnership with you. Family support will be incorporated into the tailored Intervention Care Plan and will set out the key elements required to meet the support needs of your child/young person and your family. A separate guidance document entitled: 'Support Guidance along the Lifespan', produced by the Health and Social Care Board's Regional Autistic Spectrum Disorder Network (RASDN), offers more detailed information in this area.

Specific treatments/interventions will be arranged for your child/young person based on his/her needs after the assessment has been completed, and will be provided by the Autism Service Team and relevant others (for example, non statutory agencies) in an integrated manner and may include:

- Early intervention programmes;
- Environmental adaptations;
- Education-based interventions;
- Family Support programmes;
- Functional behaviour based interventions;
- Language and communication support;
- Person-centred action plans;
- Pharmacological interventions (where appropriate);
- Co-occurring conditions, for example, epilepsy;
- Psychological support (child/young person and family), as well as family support;
- Sensory processing;
- Planning and co-ordination of transitions.

In summary, different treatments/interventions will be helpful at different stages of your child/young person's life. It is essential that any treatment/intervention offered to your child/young person and your family, is based on an in-depth assessment process, delivered by services working together, and is specific to meet your child/young person's individual needs. Regular reviews will be available to you and your family, and you will be given contact details of your link person within the Autism Service Team.

### Further information

- UK University Research Centre:  
[psych.cf.ac.uk/warc/research/](http://psych.cf.ac.uk/warc/research/)





## Understanding Behaviours

All children are different and display unique behaviours. However, some parents/carers may find it difficult to cope with particular behaviours which their children/young persons with ASD may display. Some of these may include:

- running away;
- not listening or being uncooperative;
- being destructive;
- hitting themselves or others;
- excessive emotional outbursts;
- obsessions and rituals.

### Your child/young person's view

Children/young persons with ASD are as capable of 'misbehaving' as any other child/young person. It is important, however, to understand whether your child/young person is 'misbehaving' or if their behaviour is the result of his/her ASD. To help you to begin to understand your child/young person's behaviours, you may find it useful to look for recurring patterns:-

- Has your child/young person developed behaviours that are a result of language impairment, or not being able to express desires, frustrations or anxieties?
- Is there a trigger to your child/young person's behaviour, such as an odour or noise?
- Are there health reasons for the behaviour?
- Is your child/young person expressing pain or discomfort through behaviour instead of communicating verbally or in another way?
- Is there an underlying mental health issue, which is causing your child/young person some distress?

### Brother/sisters' view

Brothers and sisters can find it difficult to understand why there might be different parent/carer responses to particular behaviours. For example, if your child/young person with ASD is misbehaving and this is allowed, but not tolerated for the siblings, this can lead to confusion and resentment. Parents/carers should be consistent in their child behaviour management.

Brothers and sisters are also a great support, and can be role models, for your child/young person with ASD.

### Communication

Give your child/young person ample opportunity to copy your



own positive behaviours. Does the way you communicate with your child/young person need to be changed? For example, you might need to speak more slowly, or you could wait longer before you expect an answer. Fewer words or use of visual aids, could improve your interaction.

If you remain calm and non-judgemental, it will be much easier to understand what your child/young person may be feeling and trying to communicate. Think about finding new ways to reduce your own individual stress levels.

### Sensory issues

Many children/young persons with ASD have difficulty processing sensory information resulting in them being over or under sensitive to taste, touch, noise, sights, smells, movement, body position and balance. This can lead to physical clumsiness, poor body awareness and high or lower activity levels.

### Co-existing conditions

Many children/young people with ASD have other medical conditions at the same time, and therefore have what is known as 'complex needs'.

These other conditions may include: epilepsy, mental health concerns, Attention Deficit Hyperactivity Disorder (ADHD) or learning disabilities.

### Further information

#### National Institute for Health and Clinical Excellence (UK) - Guidelines for Families

- [www.nice.org.uk](http://www.nice.org.uk)
- The diagnosis and care of children and adults with epilepsy; 2004: <http://guidance.nice.org.uk/CG20/PublicInfo/pdf/English>
- The treatment and depression of children and young people; 2005: <http://guidance.nice.org.uk/CG28/PublicInfo/pdf/English>
- Attention Deficit Hyperactivity Disorder; 2008: <http://guidance.nice.org.uk/CG72/PublicInfo/pdf/English>

#### Department of Health, Social Services and Public Safety – Northern Ireland

- [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)
- Review of Mental Health and Learning Disability (Northern Ireland) – Equal Lives; Department of Health, Social Services and Public Safety; 2005: [www.dhsspsni.gov.uk/learning-disability-report](http://www.dhsspsni.gov.uk/learning-disability-report)
- Review of Mental Health and Learning Disability (Northern Ireland) – Focus on Families; Department of Health, Social Services and Public Safety; 2004: [www.dhsspsni.gov.uk/index/bamford/service-users.htm](http://www.dhsspsni.gov.uk/index/bamford/service-users.htm)

#### Other Sources

- Caring for Someone with Autism: [www.nhs.uk/livewell/autism/pages/helpparentscarers.aspx](http://www.nhs.uk/livewell/autism/pages/helpparentscarers.aspx)
- Coping with Challenging Behaviour: [www.nhs.uk/livewell/childrenwithlearningdisability/pages/challengingbehaviour.aspx](http://www.nhs.uk/livewell/childrenwithlearningdisability/pages/challengingbehaviour.aspx)

***“Get some support/advice from another parent, or voluntary organisation.”***

*(Parent/Carer)*

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## Financial Support and Benefits

In recognition of the associated costs of disability, you as the parent/carer of a child/young person with ASD, can apply to your local Social Security Agency for financial support. There are a wide range of benefits available.

### Disability Living Allowance (DLA)

DLA is not means tested. It is designed for disabled individuals who have care and/or mobility needs as a result of disability.

As a parent/carer you can apply on behalf of your child/young person. You need to demonstrate the limitations that come from the disability.

The Allowance has two components (parts):

- Care component: eating; drinking; sleeping; washing; toileting; socialising; communicating and dressing;
- Mobility component: supervision; guidance outside the home, as well as physical movement limitations.

The care component of DLA has three rates - low, middle and high.

There are only two rates of the mobility component - high and low.

In order to qualify for the care component, you need to demonstrate that there has been a disability present for more than three months, and that it will last at least a further six months. The mobility component can be applied for once your child reaches the age of three.

### Applying for DLA

The completion of the form is time consuming. Make sure that you have support and advice from an experienced organisation/welfare rights adviser. You may need to arrange a prior appointment. A decision will be made based on the evidence submitted on your DLA form. The DLA office will seek additional information from 'someone who knows your child/young person best'.

Your ASD Co-ordinator can provide you with further information on applying for DLA, as well as a list of local voluntary and charitable organisations which may be of help to you.



## Motability Scheme

If your child/young person is awarded DLA, you as parent/carer may be able to apply on his/her behalf for help and support with leasing a car. This is known as the Motability Scheme. If you apply for this, your child/young person must currently receive the higher rate mobility component of DLA, and he/she must have at least 12 months remaining of the DLA award.

## Blue Badge Scheme

This entitles you to parking concessions and allows you to park close to your destination. This can be used within the UK, and throughout the European Union (EU).

You can obtain the badge if your child/young person receives the higher rate of the mobility component of DLA. Other criteria may apply. If your child/young person was not awarded DLA, you have the right to ask for your application to be reconsidered.


## Further information

### Northern Ireland Direct

- Motability Scheme: [www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/people-with-disabilities-motoring-and-transport/your-vehicle-and-licence/the-motability-scheme.htm](http://www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/people-with-disabilities-motoring-and-transport/your-vehicle-and-licence/the-motability-scheme.htm)
- Beginners Benefits Guide: [www.nidirect.gov.uk/index/information-and-services/money-tax-and-benefits/benefits-and-financial-support/beginners-guide-to-benefits.htm](http://www.nidirect.gov.uk/index/information-and-services/money-tax-and-benefits/benefits-and-financial-support/beginners-guide-to-benefits.htm)
- Blue Badge Scheme: [www.nidirect.gov.uk/index/people-with-disabilities/motoring-and-transport-1/blue-badge-scheme/the-blue-badge-parking-scheme.htm](http://www.nidirect.gov.uk/index/people-with-disabilities/motoring-and-transport-1/blue-badge-scheme/the-blue-badge-parking-scheme.htm)

### Other Sources

- Social Security Agency – A-Z of Benefits: [www.dsdni.gov.uk/index/ssa.htm](http://www.dsdni.gov.uk/index/ssa.htm)
- Direct Gov - Disability Living Allowance: [www.direct.gov.uk/en/disabledpeople/financialsupport/dg\\_10011925](http://www.direct.gov.uk/en/disabledpeople/financialsupport/dg_10011925)



*“Know your rights and claim what is yours.”*

(Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

## Social and Leisure Activities

All children/young persons need social and leisure activities. For example, exercise improves mental and physical well-being as well as motor skills. Physical activity can support the development of social skills and broaden inclusion opportunities.

Children/young persons with ASD may have to learn skills to help them play and participate in leisure activities. There are organisations that have inclusive social and activity groups where your child/young person will have the opportunity to be with and engage with his/her peers. If your child/young person needs assistance to access these activities, there may be befriending schemes, that help to foster your child/young person's involvement and inclusion.

### Choosing activities

You should encourage your child/young person to try a range of different activities in order to find the one they particularly enjoy.

Children/young people's social groups may help your child/young person to interact socially and learn social skills. Ask the Group Leader what support/advice is needed to involve your child/young person in the activity/group?

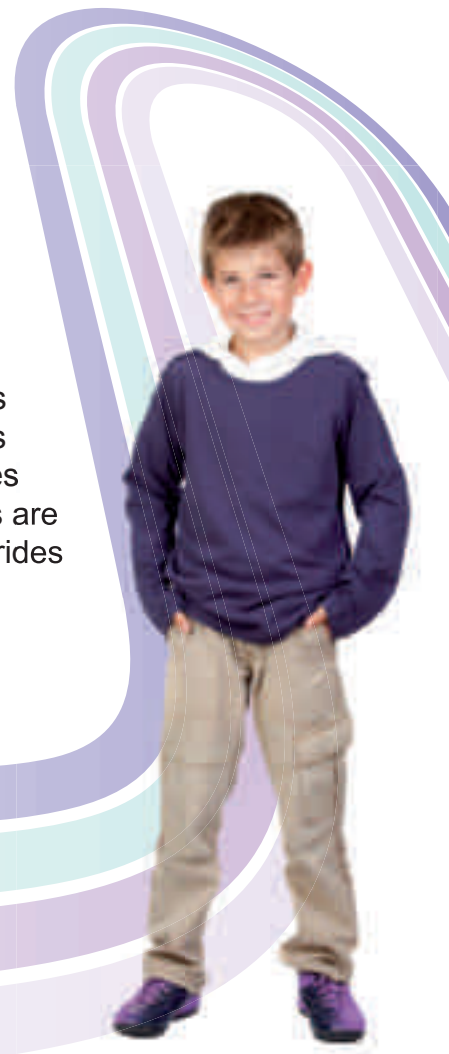
There may be concessions available for your child/young person and the accompanying carer.

### Family activities

Enjoying time together is important for all families. Everyday activities that the family can participate in are excellent learning opportunities for your child/young person. Even trips to the supermarket or bank, present opportunities to learn about daily living skills.

### Tips for successful trips away/holidays

Many attractions and leisure facilities offer assistance to families who have children/young persons with disabilities. You can find out about the level of support offered before you leave home by asking other parents of children/young persons with ASD about their experiences, or by checking out websites and telephoning for more information. You can request policies regarding admission and queueing, and ask what adjustments are made for individuals with disabilities such as reserving seats, rides or parking spaces.




## Access

Should any problems arise regarding your family's access to facilities, sports or social groups, you can lodge a complaint under the Disability and Equality (NI) Order 2006 and its amendments.

## Further information

- Equality Commission for Northern Ireland – Disability Discrimination: [www.equalityni.org/sections/default.asp?cms=Your+Rights\\_Disability+discrimination&cmsid=2\\_142&id=142&secid=2](http://www.equalityni.org/sections/default.asp?cms=Your+Rights_Disability+discrimination&cmsid=2_142&id=142&secid=2)
- Local Councils: [www.nidirect.gov.uk/index/contacts/local-councils-in-northern-ireland.htm](http://www.nidirect.gov.uk/index/contacts/local-councils-in-northern-ireland.htm)



*“Enjoy your child and their interests.  
It’s really good fun. You will find their  
strengths.”*

*(Parent/Carer)*

Contact the Autism Service Team/ASD  
Co-ordinator at your local Health and Social Care  
Trust, for further Guide information and details of  
services available.

# Adolescence

## Diagnosis

Your young person may recently have received a diagnosis of ASD, and will have followed the process outlined in an earlier section of this guide entitled: 'ASD Diagnosis – What to Expect'.

Some of the signs and symptoms of ASD in adolescence are:-

- reduced/absent understanding of friendships;
- long standing history of difficulties with behaviour and social communication;
- he/she may take things literally;
- he/she makes comments without awareness of social manners;
- social isolation and apparent preference for aloneness;
- social and emotional development more immature than other areas of development;
- highly repetitive behaviours;
- preference for highly specific interests or hobbies.

**(Source: National Institute for Clinical Excellence Guidelines, 2011)**

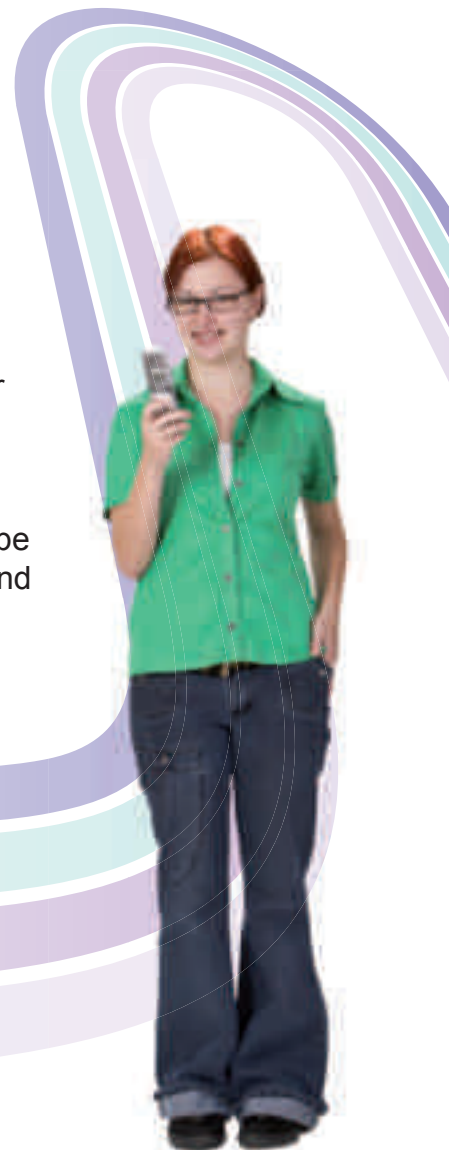
Every parent/carer will want to ensure their young person becomes as independent as possible.

Your young person will encounter many changes throughout adolescence and adulthood. New routines and strategies to cope with these changes, need to be established early on, and be transferable to different situations.

Flexible routines to do with dressing, greeting people and awareness of strangers are best established at an early age.

Moving into adolescence is called a transition stage. Transitions do not just take place at school. Planning for a successful transition includes all aspects of the life of your young person as he/she gets older. The skills required by your young person to transition successfully into adulthood, can be learned in a range of environments.

Showing your young person that you believe in their ability to be an independent adult, will help to build their self confidence, and encourage and motivate him/her to participate in the transition process wherever it takes place.



There are everyday skills that your young person may need to learn such as: self-help skills; cleaning the house; buying items in shops; preparing and storing food; maintaining nutrition; shopping for clothes; paying bills; maintaining personal hygiene and using public transport .

Your young person may need to learn how to problem solve, compare options, plan, and follow through on tasks and decisions.


Mobile phone and computer applications for ASD may be useful for your young person as they can teach daily living skills. These programmes can be individualised to your young person's needs and may help in explaining what to do in certain situations.

For every skill your young person learns, you should be thinking about the things that could go 'wrong' and build in ways for them to be flexible and to cope with change. It is important to provide your young person with frequent opportunities for feedback. This will help to build self-esteem in your young person. Regular review of achievements and celebration of any successes, will help strengthen your young person's desire to continue to learn and acquire skills.

Many of the skills your young person needs to acquire can be taught at home, but they can also be taught by a life skills mentor or coach. Your ASD Co-ordinator at your local Health and Social Care Trust will have details of local training sources.

### Further information

- Department of Health, Social Services and Public Safety – Top Tips for Parents: [www.dhsspsni.gov.uk/public\\_health-toptips](http://www.dhsspsni.gov.uk/public_health-toptips) - (click on the teenage link).
- Department of Employment and Learning – Careers Service: [www.delni.gov.uk/index/publications/del-response-to-recession/careers-service.htm](http://www.delni.gov.uk/index/publications/del-response-to-recession/careers-service.htm)
- Education Support for Northern Ireland -Transition Service: [www.education-support.org.uk/parents/special-education/transition-service/](http://www.education-support.org.uk/parents/special-education/transition-service/)
- National Institute for Health and Clinical Excellence - ASD in Children and Young People (2011) (in progress): <http://guidance.nice.org.uk/CG/Wave15/78>



*“Allow yourself to dream of what you think would be a good future for your child, ask others to dream too.”*

(Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## Rights, Benefits and Housing

### Rights

The law in Northern Ireland must be in line with European and International law and conventions which are rights based.

These laws include:

- The Northern Ireland Human Rights Act (2000)
- The Northern Ireland Act (1998) (Section 75)
- The Disability Discrimination Act (1995) (DDA)
- The European Convention on Human Rights (ECHR)
- The UN Convention on the Rights of the Child (UNCRC)
- The UN Convention on the Rights of Persons' with Disabilities (UNCRPD)
- All public bodies in Northern Ireland must give consideration to the rights of those with whom they engage and have a responsibility in respect of consultation and screening in relation to any policy which may impact upon any of the groups as contained within section 75 of the Northern Ireland Act (2000).

### Benefits

Families of a young person with ASD may be entitled to receive some of the following benefits.

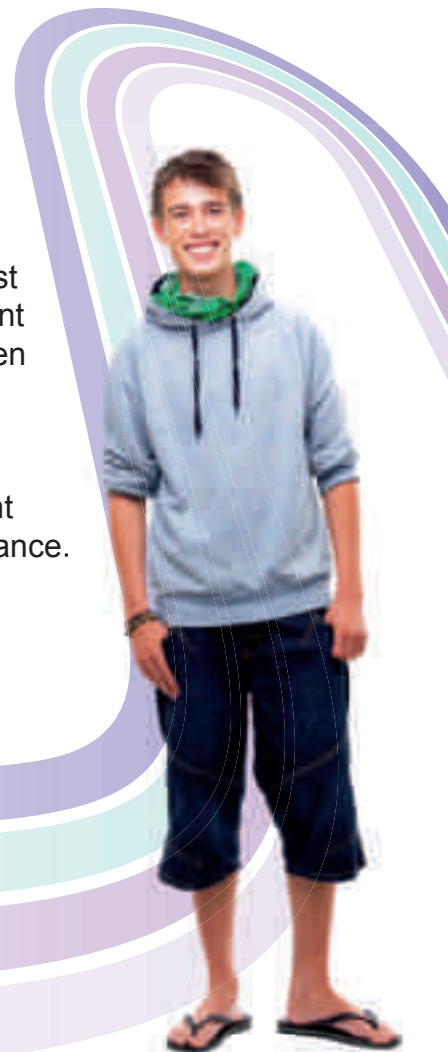
#### **Disability Living Allowance**

Disability Living Allowance (DLA) is designed for disabled individuals who have care and/or mobility needs. See earlier section in this Guide entitled: 'Financial Support and Benefits', for further details.

Your young person's award will be reviewed at age 16 years on an ongoing basis. You can apply for DLA on behalf of your young person. At the age of 16 years the DLA process changes. Families, if necessary, can have official appointee status from DLA to continue to manage their young person's benefit, with their consent, or on the basis of acting in their best interest on the basis of competency where such an assessment has been undertaken. In such situations advice should be taken from the relevant agency.

#### **Employment Support Allowance**

Depending on your young person's education and employment options he/she may also apply for Employment Support Allowance. This award replaced Incapacity Benefit.



Qualification for other benefits and support are available for those who are actively seeking work, such as the Access to Work (NI), Work Preparation or Workable (NI) programmes.

For more information and advice you can contact your Employment Service Adviser at your local Jobs and Benefits Office, and ask to discuss your young person's needs. You may also wish to speak to an independent advice service.

## Housing

**Housing Benefit** - Individuals on low incomes can apply for help with paying rent or rates.

**Disabled Person's Allowance** - If you have had to make adaptations to your home because of your young person's disability, you may be entitled to a rates rebate. This may include an additional bathroom, therapy room, downstairs bedroom or extension to facilitate more independent living. It is not means tested.

**Disabled Facilities Grant** - You may also be entitled to a Disabled Facilities Grant. This grant is intended to help improve the home of a person with a disability to make it more suitable for him/her to live in. Only applications supported by an Occupational Therapist can be granted. You must contact your local Health and Social Care Trust to initiate the process. It is not applicable if you are a Housing Executive tenant.

**Supported Housing** - If your young person does decide to leave home and live independently, there are some organisations that can offer help and advice. Your ASD Co-ordinator can provide you with this information.

Remember that this future stage of your young person's life must be discussed and included in their Transition Plan. This will help to ensure that all professionals involved with your young person, communicate better with each other and plan more effectively for future needs.

For all children/young people with a Statement of Special Educational Needs there is a formal process in relation to transition in line with The Special Educational Needs and Disability (NI) Order (2005). Reference to this Order is contained within the section on Educational Needs within this Guide.

## Further information

### Rights

- Equality Commission for Northern Ireland – Disability:  
[www.equalityni.org/sections/default.asp?cms=your%20rights\\_Disability%20discrimination&cmsid=2\\_142&id=142&secid=2](http://www.equalityni.org/sections/default.asp?cms=your%20rights_Disability%20discrimination&cmsid=2_142&id=142&secid=2)
- Northern Ireland Commissioner for Children and Young People:  
[www.niccy.org](http://www.niccy.org)
- Northern Ireland Human Rights Commission  
[www.nihrc.org/](http://www.nihrc.org/)

### Benefits

- Northern Ireland Direct - Jobs and Benefits Offices:  
[www.nidirect.gov.uk/index/contacts/jobs-and-benefits-offices.htm](http://www.nidirect.gov.uk/index/contacts/jobs-and-benefits-offices.htm)
- Northern Ireland Direct – Benefits Adviser: [www.nidirect.gov.uk/index/do-it-online/money-tax-and-benefits-online/benefits-adviser.htm](http://www.nidirect.gov.uk/index/do-it-online/money-tax-and-benefits-online/benefits-adviser.htm)
- Department of Social Development – Social Security Agency: [www.dsdni.gov.uk/index/ssa.htm](http://www.dsdni.gov.uk/index/ssa.htm)
- HM Revenues and Customs - Tax Credits: [www.hmrc.gov.uk/taxcredits](http://www.hmrc.gov.uk/taxcredits)

### Housing

- Northern Ireland Housing Executive – Who Can Claim Housing Benefit? [www.nihe.gov.uk/index/housingbenefit/housing\\_benefit\\_advice/housing\\_benefit\\_claims.htm](http://www.nihe.gov.uk/index/housingbenefit/housing_benefit_advice/housing_benefit_claims.htm)
- Department of Finance and Personnel – Land and Property Services:  
[www.dfpni.gov.uk/lps](http://www.dfpni.gov.uk/lps)

*“Be ambitious!  
You can make a  
difference.”*

(Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## Moving into Adulthood

### Planning for the future

In order for your young person to achieve academically and progress towards independent adulthood, it is best to start to think about the steps that both of you need to take in the next few years. You must start early, preferably as soon as your young person enters post-primary education. This process is referred to as 'transition'. Your young person needs to experience transition from adolescence to adulthood in as smooth a way as possible. Many important decisions must be made about his/her future; education, training, employment and independence during this period.

Throughout this process your young person should be encouraged to consider which skills they need to acquire, to realise their own hopes and attain their aspirations for the future.

Central to effective transitioning will be the need for local Health and Social Care Trusts to adopt a Person-Centred Approach and agree a Person-Centred Plan. Health and Social Care Trusts will also offer you a Carer's Assessment as part of the integrated Family Support Plan.

### The 'Transition Plan' in education

As stated in an earlier section of this Guide entitled: 'Educational Needs', an Education Plan (EP) will be provided by your young person's teacher if he/she has educational needs. The EP is used to deliver and monitor the achievement of specific goals and objectives.

Your young person will have an EP which details the extra support that he/she will receive, and will address issues such as the development of skills in communication, social interaction, literacy and mathematics.

If your young person has a Statement of Special Educational Needs, his/her school must carry out a formal transition assessment with other agencies, which generates a detailed plan. This process is commenced by the school, at age 14 or later, and the plan is reviewed annually.

The Transition Plan outlines all the steps to be covered in the transition process from adolescence to adulthood. It lists all of the relationships and connections made on behalf of your young person with other agencies or educational institutions.



You will receive a copy of the Transition Plan with the names of individual practitioners who are responsible for co-ordination of support. It is vital that at every stage, the Transition Plan is discussed, developed and communicated to everyone involved with your young person. Parents/carers will be asked to give their consent for the plan to be circulated by the Education and Library Board, to relevant parties who may be involved after the young person leaves school.

If a young person leaves school at the age of 16, his/her Statement is no longer legally binding.

### Good transitions checklist

1	Is your young person fully involved in the transition planning and process?
2	Is your young person fully aware why the transition process is so important?
3	Are your young person's hopes and aspirations being acknowledged?
4	Does he/she have, and continue to have, all the information they need?
5	Has consideration been given to training for independent travel?
6	How do you know if your young person is able to use and generalise new knowledge and skills, across different situations?
7	How are you reducing his/her fears/concerns regarding change?
8	Are you incorporating and using all your young person's strengths?
9	Do you praise your young person for trying to learn new skills?
10	Are you providing the skills that will help him/her 'fit in' with peers and the community in general?
11	Who will provide support to your young person after the transition process has formally ended?
12	Does your young person know who they should contact in adult services?

### Transition from children to adult services in Health and Social Care Trusts

Following your young person's transfer from children's to adult services, a review of their transition support arrangements will be undertaken. You and your young person will be involved in this review.

### Further information

- Education Support for Northern Ireland - Transition Service:  
[www.education-support.org.uk/parents/special-education/transition-service/](http://www.education-support.org.uk/parents/special-education/transition-service/)
- Minding Your Head Info: [www.mindingyourhead.info/young-people/young-people](http://www.mindingyourhead.info/young-people/young-people)

*“Have a plan to support your child towards independence - as a learner, having a social life, living in their own home.”* (Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## Choices for Post 16 Education

There are a wide range of options available for post-16 education. Your young person may choose to attend their own school until the age of 18/19 years, or he/she might decide to attend a further education college, university, a specialist training course or supported employment. They might also enrol in an apprenticeship.

Should he/she wish to remain in school until they are 18, and they have a Statement of Special Educational Needs, the Transition Plan that has been agreed will continue to be implemented within the school. Following a young persons completion of secondary level education his/her Statement of Special Educational Needs is no longer legally binding.

### Further education

The detailed Transition Plan will provide useful information for Further Education (FE) and/or employment support. Your young person's educational choices should be included in the Transition Plan, and this can be used by his/her new educational provider or work place, to make suitable arrangements. Support at a FE college can include:

- learning mentors;
- sign language interpreters;
- note-takers;
- loan of equipment;
- specialist enabling technology; and
- examination support.

Remember that your young person does not have to disclose their disability to the FE college but by doing so may help them to receive the support they need to make the experience at college a successful one.

To help make transition as smooth a process as possible:

- Meet with the Disability Services Advisor at your local Education and Library Board to discuss any additional support that your young person might need, especially at enrolment time.
- Allow plenty of induction time so that your young person can find their way around the new environment.
- Ensure ASD training is included in the Transition Plan so that staff and new employers get training.



- If there is an allocated support worker, give your young person time to get to know them and to discuss their support needs.
- Discuss your young person's needs with the lecturer/tutor and explain what difficulties he/she may have, such as note taking skills or processing time.
- Ask for materials in advance of the class so your young person has the time to read and process information.
- Explain what is acceptable clothing to wear to college.
- Check if there is a quiet area to go to, should your young person begin to feel anxious.
- Make a list of contact details of support services.

## Higher education

For a young person preparing to attend their first choice of university, it is essential you contact the Disability Services Department/Student Support Services. If you are successful in gaining a university place, Disability Services will invite you (and your parent/carer if appropriate/requested) to an interview where an assessment of your educational needs will be carried out. The range and type of support required will be discussed and detailed in writing. This application for Disabled Student Allowance (DSA) will be forwarded to your local Education and Library Board (ELB). If this level of funding is agreed, your Disability Officer will contact you or your parent/carer to ensure all the necessary supports are put into place.

Students will have an Advisor of Studies to whom they can liaise regarding any academic concerns. Student Unions provide a range of support services which may include benefits advice, counselling and a wide range of recreational activities.

Young people attending university, away from home, may choose to join a local General Practitioner surgery.

## Further information

- Northern Ireland Direct - Disability Support at College: [www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/learning-and-education/support-at-college-or-university/disability-support-at-college.htm](http://www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/learning-and-education/support-at-college-or-university/disability-support-at-college.htm)

## Further Education Links

- Belfast Metropolitan College: [www.belfastmet.ac.uk/StudentServices/DisabilityServices/Default.aspx](http://www.belfastmet.ac.uk/StudentServices/DisabilityServices/Default.aspx)
- North West Regional College: [www.nwrc.ac.uk/](http://www.nwrc.ac.uk/)
- Northern Regional College: [www.nrc.ac.uk/](http://www.nrc.ac.uk/)
- Southern Regional College: [www.src.ac.uk/](http://www.src.ac.uk/)
- South Western Regional College: [www.swc.ac.uk/](http://www.swc.ac.uk/)
- Southern Eastern West Regional College: [www.serc.ac.uk/](http://www.serc.ac.uk/)

## Higher Education Links

- Queen's University – Disability Services: [www.qub.ac.uk/directorates/sgc/disability/](http://www.qub.ac.uk/directorates/sgc/disability/)
- University of Ulster – Student Support: [www.studentsupport.ulster.ac.uk/disability/disability.html](http://www.studentsupport.ulster.ac.uk/disability/disability.html)

*“Having ASD means I am an expert in my specialist area of interest and that means others can be jealous of me for having such enhanced knowledge.”* (Young Person with ASD age 15)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## Supporting Employment Opportunities

There are many support agencies that can provide your young person with training opportunities and support, so that the experience of finding and keeping a job is more positive.

### Supported training and education

The agencies that help with finding training and employment opportunities can also help your young person once he/she has a job.

These agencies can offer:

- mentoring and coaching opportunities, as well as support in the workplace;
- training for your employer, so he/she can make 'reasonable adjustments' to your job and workplace, to meet your needs;
- training staff in ASD awareness.

It is unlawful for an employer to harass an employee or a job applicant, for a reason which relates to a disabled person's disability.

### Bring in extra help from support organisations

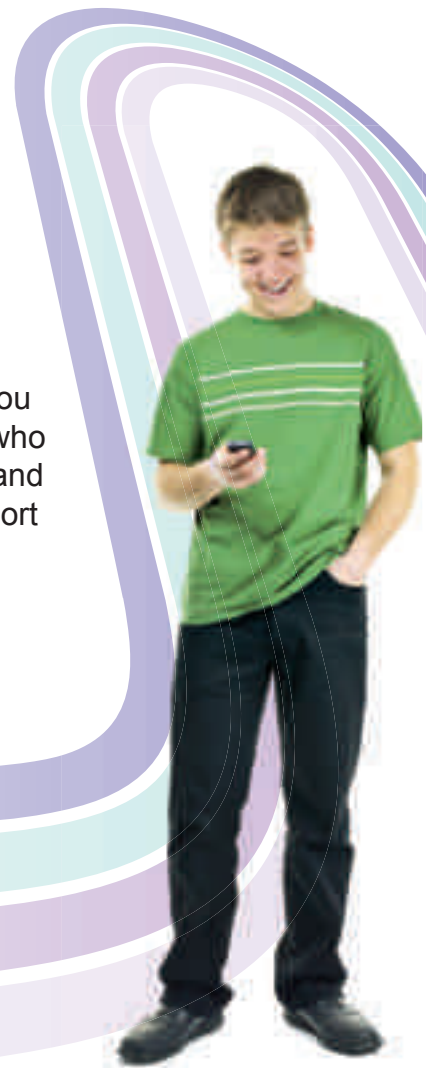
Help from support providers is beneficial for the employer and the employee with ASD. The chances of being successful in a work placement or a job, can be improved by support and advice from these organisations.

A job coach or mentor, can support your young person in the workplace, especially at the beginning of his/her employment. He/she may be from a support organisation, or be a colleague who has awareness and training in ASD.

The Department of Employment and Learning (DEL), through its Disability Advisory Service helps individuals with complex needs and/or serious conditions, into training and employment.

### Learning disability support

If your young person has both ASD and a learning disability, you can access help and advice from a number of organisations, who work specifically in this area, and who carry out programmes and training on behalf of DEL. These specialist organisations support individuals with learning disabilities to gain work experience, training and employment.



## Disability Discrimination

It is unlawful under the Disability Discrimination Act 1995 (DDA) and Disability Discrimination (Northern Ireland) Order 2006, to discriminate against a person with a disability in employment, or when looking for employment, on the grounds of their disability.

It is unlawful for an employer to discriminate in:


- recruitment and selection, including arrangements for deciding who should be offered employment, in the terms on which employment is offered, or by refusing or deliberately omitting to offer a person employment; and
- the terms and conditions of employment.

Reasonable adjustments for interview and in the workplace

- An employer has a duty to make reasonable adjustments, so as not to place a person with a disability at a substantial disadvantage, compared with a person without a disability.
- In the workplace, reasonable adjustments would be ensuring that proper training takes place, allowing a mentor or job coach to work in partnership with the employer and your young person, or arranging ASD awareness training for other staff to reduce any concerns or misunderstandings.

## Further information

- Department of Education and Learning - Employing People with Autism:  
[www.delni.gov.uk/search.jsp/search.lsim?sr=0&nh=10&cs=iso-8859-1&sc=&sm=0&mt=1&ha=del-cms&qt=+autism](http://www.delni.gov.uk/search.jsp/search.lsim?sr=0&nh=10&cs=iso-8859-1&sc=&sm=0&mt=1&ha=del-cms&qt=+autism)
- Northern Ireland Direct - Work Schemes and Programmes:  
[www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/employment-support/work-schemes-and-programmes.htm](http://www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/employment-support/work-schemes-and-programmes.htm)
- Equality Commission for Northern Ireland – Disability Discrimination:  
[www.equalityni.org/sections/default.asp?cms=your%20rights\\_Disability%20discrimination&cmsid=2\\_142&id=142&secid=2](http://www.equalityni.org/sections/default.asp?cms=your%20rights_Disability%20discrimination&cmsid=2_142&id=142&secid=2)



*“The child with autism will be successful and hopefully the autistic child will be able to have fun in life as well as making friends.”* (Adult Service User)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## Inclusion

Your young person with ASD needs physical activity and social engagement during adolescence, as much as, if not more than, at other stages of their life. Exercise can improve mental and physical well-being, reduce frustration, increase opportunities for social engagement, help social skills and is generally good fun.

### Physical activity

Physical activity should be encouraged. Check with your local leisure centre for information on classes being offered. Some schemes offer discounted rates for both young people with a disability and an accompanying carer. Local voluntary organisations also run various activities/courses.

### Social activities

Many organisations offer community inclusion programmes including arts, sports, hobbies, drama and health and well-being classes.

Contact your local leisure centre for further information.

### Befriending services

A befriending service is a scheme where vetted and trained volunteers help support people with ASD and their families.

Examples of support:

- accompanying a young person to an activity class or youth club;
- going out to the park, or for a walk;
- meeting an adult for lunch, or a trip to the cinema;
- helping with shopping trips;
- listening to a family member when he/she needs to talk;
- caring for an individual with disabilities in the family home, which allows parents/carers to go out for a short break;

Many families appreciate this type of flexible support/ respite.

All the activities mentioned above should be open/accessible to individuals with disabilities. You do not have to disclose your young person's disability, but you may find that if you do, adjustments for him/her can be made.



There are many organisations which organise ASD-specific and socially inclusive activity clubs. The skills acquired can help your young person feel more confident and motivated to engage in future activities.

### Accessing Health and Social Care Trust services

Families can contact their ASD Co-ordinator for information on leisure and social activities available within their local area.

In addition, families may be able to use the Direct Payments Scheme to help with support in accessing leisure and social activities in their local area. Direct Payments are cash payments, made in lieu of social service provisions, to individuals who have been assessed as needing services. Direct Payments increase choice and promote independence. For further information on Direct Payments see section entitled: 'Support for your Family' within this Guide.

### Peer support

The Autism Service Team at your local Health and Social Care Trust will have a list of local support services/organisations who are experienced in providing peer support for young persons with ASD.

### Further information

- Public Health Agency - Physical Activity: [www.publichealth.hscni.net](http://www.publichealth.hscni.net)
- Northern Ireland Direct -Travel Safe:  
[www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/people-with-disabilities-motoring-and-transport/public-and-community-transport/travel-safe.htm](http://www.nidirect.gov.uk/index/information-and-services/people-with-disabilities/people-with-disabilities-motoring-and-transport/public-and-community-transport/travel-safe.htm)
- Local Councils: [www.nidirect.gov.uk/index/contacts/contacts-az.htm/local-councils-in-northern-ireland](http://www.nidirect.gov.uk/index/contacts/contacts-az.htm/local-councils-in-northern-ireland)

*“Your child will surprise you with what they can achieve.”*

(Parent/Carer)

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.



## Understanding Others

Our world is full of unwritten social rules that most people naturally understand. Children start to learn from an early age the kinds of behaviour others expect from them in different situations. We do not generally have to be specifically taught social rules. We also understand the consequences of breaking those rules.

These rules are sometimes referred to as the 'hidden curriculum', and lack of understanding in this area can result in your young person with ASD having difficulty making and maintaining friendships. This rejection with resulting loneliness, may result in your young person experiencing low self- esteem and depression.

If you understand the hidden curriculum you know:-

- how and when to take turns speaking with others; and
- how much personal space to leave between yourself and another person.

Your young person may not be able to interpret social rules, subtle signs or non-verbal cues coming from others. He/she may instead unknowingly 'break' these rules. Also your young person may not be able to grasp how and when, to 'bend' these rules.

When this happens, others may misread the words and actions of your young person. As your young person starts to interact in mainstream life, it is important to ensure he/she is made aware of these unwritten rules.

### Developing friendships

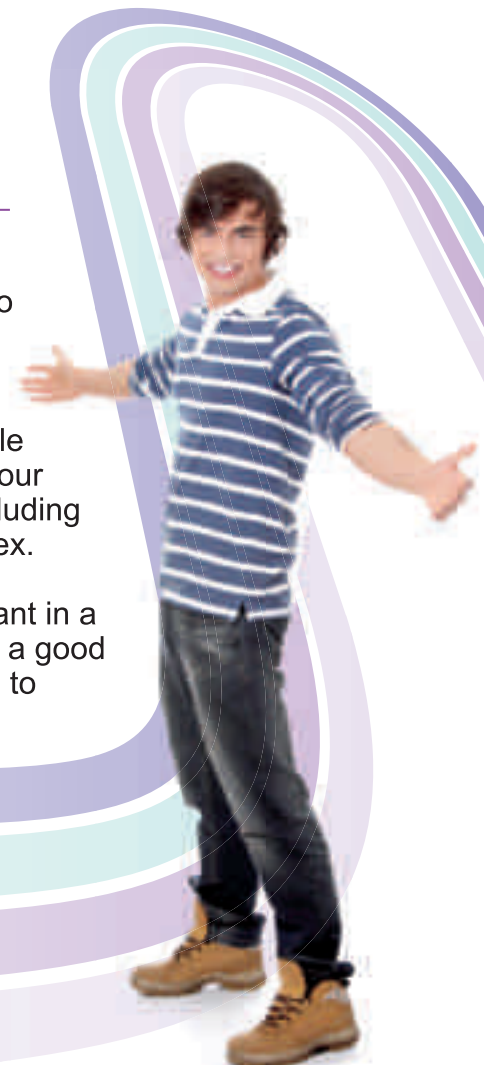
Explain to your young person that forming friendships will be important throughout their lives, and that a true friend is someone who would never harm them or place them in danger. Share this easy read guide with your young person to help keep him/her safe.

[www.west-midlands.police.uk/saferstreets/downloads/keep\\_safe.pdf](http://www.west-midlands.police.uk/saferstreets/downloads/keep_safe.pdf)

Like all teenagers, your young person with ASD may want to be part of a social group, or perhaps just want a one-to-one friendship.

If your young person is socially naive he/she may not be able to understand the motives and intentions of others. Teach your young person how to engage appropriately with friends, including how he/she should interact with members of the opposite sex.

Ask your young person what are the qualities they would want in a friend. Help him/her to think about, and then practice, being a good friend. Provide ongoing opportunities for your young person to develop friendship skills.



## Developing sexual relationships

The teenage years are a time of changing emotions and growing awareness of sexual development. Your young person is becoming an adult, and may be interested in forming romantic relationships. If your young person has difficulty with social rules or cues, he/she may also have additional difficulty relating to members of the opposite sex.

Sensitively discuss sex education, relationships and sexuality with your young person. Outline the appropriate behaviours which young persons use when they want to show that they admire or like someone. Clearly explain what is appropriate and what is not.

Specialist advice should be sought for those young persons who also have a learning disability. Your ASD Co-ordinator can advise you who best to contact.

Encourage and support your young person to ask questions about this important subject. Remember that interest in this area may be delayed until early adulthood, and you may have to revisit these discussions at a later stage.

## You and the law

Due to their social naivety, young persons with ASD are more vulnerable to having criminal acts being committed against them.

Prepare your young person, on how to respond appropriately to the police, if stopped. It is helpful to carry what is known as an 'Autism Alert Card'. This card outlines any medical condition(s) of the individual, immediate support required, as well as giving emergency contact details of the young person. It can be obtained free of charge online, from a number of voluntary organisations.

Your young person may be more rigid in his/her understanding of what is legal or illegal. Sometimes his/her unusual behaviour may draw attention from the police, and maybe misinterpreted as threatening or violent. It is often the case that individuals with ASD do not realise the impact of their behaviour on others, and the implications of their actions. They may also find themselves in contact with the police more than once, due to an inability to learn from previous situations.

So, as with any of your other children – it is important to keep yourself informed about where

Contact the Autism Service Team/ASD Co-ordinator at your local Health and Social Care Trust, for further Guide information and details of services available.

your young person with ASD spends their free time, and who they spend it with.

It is important that you as a parent/carer, know your young person's rights should he/she come into contact with the Youth Justice System.

## Further information

- Youth Justice Agency – Youth Justice System:  
[www.youthjusticeagencyni.gov.uk/youth\\_justice\\_system/](http://www.youthjusticeagencyni.gov.uk/youth_justice_system/)
- Police Service of Northern Ireland:  
[www.psni.police.uk](http://www.psni.police.uk)

*“ASD is only one of many labels people use to define difference. I am male, white, 5ft 11, a teenager, have red hair, wear glasses and at this moment I have spots. I wear tops with hoods on. I think designer clothes are overpriced and are unnecessary and I like music others don't.”*

(Young Person with ASD)

