

Information for Parents/Guardians of Children and Young People with a Physical Disability

The aim of this pamphlet is to inform parents and guardians of supports and services available for children and young people with a physical disability and their families.

The early days

How do you find out if your baby or young child has a physical disability?

Physical disability in babies and young children is generally discovered either at birth or through early child developmental checks carried out by public health nurses on all babies in the local health centre at 9 months, 18 months and two years of age. Alternatively a hospital paediatrician may conduct the assessment.

Physical disabilities may arise from conditions such as spina bifida, hydrocephalus, muscular dystrophy, cerebral palsy, brittle bone, haemophilia, cystic fibrosis, or other conditions at birth. Physical disabilities may also be caused by severe accidental injury or brain injury.

If you have any concerns about your child's physical development you should immediately raise these concerns with your public health nurse or with your local GP. If necessary they can arrange a referral to an Early Intervention Service provided by the Health Service Executive or by an HSE-funded voluntary organisation such as the Central Remedial Clinic or Enable Ireland. Services differ from region to region and depend on the nature of your child's disability.

Early intervention

It is very important for young children with a physical disability to receive support as early as possible in life to assist their development. As a parent, you can support your child to become as independent as possible from an early age. Professionals with expertise in early childhood development and physical disability can in turn support you in your parenting.

HSE Early Intervention Teams work with families to find out how they can best support them. Members of the teams vary but may include a physiotherapist, speech and language therapist, occupational therapist, psychologist, social worker, early educator, nurse and paediatrician. Some of the services and supports to enable your child to achieve maximum independence could, depending on your child's needs, include therapy for the individual child or in groups, information and courses for parents and equipment to help the child's mobility or technical aids such as a computer to assist with school work.

Assessment of Need

The parents of any child born after 1st June 2002 may apply to the HSE for an Assessment of Need under the Disability Act if they think that their child may have a disability. Following the assessment, the parents will receive an Assessment Report stating their child's needs, if any, and the services required to meet those needs. Where a need for health supports is identified, a service statement is prepared which specifies the health services to be provided to the child, with reference to available resources.

Getting support

If you discover that your child has a physical disability you should immediately seek the support that is available to you. As well as from the Health Services, support can come from family, friends and from other parents/guardians who have children with physical disabilities. You might also consider making contact with support organisations who can offer advice and guidance to parents.

People nowadays often use the Internet as a source of information. Please bear in mind that sometimes information on the internet can be exaggerated, misleading or wrong. In matters concerning your child's health and education, you should seek information and advice from the appropriate professional sources.

Your Child's Education

Children with physical disabilities receive support in schools and many achieve positive outcomes and go on to further and higher education. A child can have a physical disability but have no special educational needs which require additional supports in schools. A child with a very severe physical disability may have mild learning needs while a child with a mild physical disability could have severe learning needs.

Pre-school

The State funds a free pre-school place for all eligible children (ECCE Scheme) in the year prior to starting school, including children with physical disabilities. More details are available on www.dcya.gov.ie. If your child is attending an early intervention service, they may be able to advise you on choosing a pre-school and on any extra support your child may need.

Primary and Post-Primary School

The vast majority of children with physical disabilities attend their local mainstream primary and post-primary schools and follow the same curriculum as every other student. A small number, with more complex needs, may attend a special school or special class for children with special educational needs. Special schools and classes have smaller class sizes.

Depending on the nature of your child's disability, you may need to check with the school Principal that the school is accessible for your child (playgrounds and toilets as well as classrooms and assembly areas). The school may apply for a grant to make the premises accessible by, for example, putting in ramps or accessible toilet accommodation. Your child may be supported in school in the following ways:

- The classroom teacher supports students with special educational needs and may adapt lessons or tasks to suit the pupil, as necessary.
- Resource and learning support teachers are available to provide additional teaching, if it is required.
- Students who have significant care needs arising from a physical disability may have access to support from special needs assistants (SNAs). SNAs look after the care needs of children while the teacher is responsible for teaching the child. Care needs can include clothing, feeding, toileting and mobility. Care support can range from assistance for a short period each day to full-time assistance depending on needs. The circumstances in which SNAs are allocated for pupils with special educational needs are detailed in Circular 0030/2014, available on the DES website at: www.education.ie.
- Assistive Technology, for example laptop/tablet computers with associated modified software, joysticks, keyboards, touch pads (see DES Circular 0010/2013).
- Special school transport arrangements, including escorts and safety harnesses where necessary, is available for eligible children.
- Schools are grant-aided to fund special items of furniture and equipment that are approved by the DES .

- School building adaptations where necessary, for example the installation of lifts, ramps or hoists.
- Reasonable Accommodation in Certificate Examinations (RACE) may be available for students with permanent or long-term conditions that will significantly impair their performance in the examinations. For more information, see the website of the State Examinations Commission at: www.examinations.ie.

Special Educational Needs Organisers (SENOs)

SENOs provide a direct service to the parents of children/young people with special educational needs and to schools. SENOs approve additional teaching and SNA supports to schools, where necessary, to support students with special educational needs. SENOs are a valuable resource to parents in the following ways:

- Providing support and advice.
- Identifying possible school placements for your child.
- Liaising with the school, the HSE and other services.
- Assisting in planning the transition of children to school, between schools and onwards from school.

A full list of SENOs and their location is available on www.ncse.ie.

Department of Education and Skills: Policy

The Department's policy is focused on ensuring that all children, including those with physical disabilities, can have access to an education appropriate to meeting their needs and abilities. The policy is to provide for children with special educational needs, including those with physical disabilities, to be included in mainstream schools unless such a placement would not be in their best interests or the interests of the children with whom they are to be educated. Some children with more complex special educational needs may be supported in a special class in a mainstream school. These children have the option, where appropriate, of full or part-time inclusion and interaction with other children. Other children may have such complex needs that they are best placed in a special school.

Health services for your school aged child

The HSE and the non-statutory services (such as Enable Ireland or the Central Remedial Clinic) provide health services and supports for school age children, including therapists and social workers. As far as possible the health professionals will work closely with the school to provide a holistic approach to your child's needs for support. You may be transferred from the Early Intervention Team to your local School Age Team when your child starts school or you can contact your paediatrician or HSE Disability Services Manager to find out about the services in your area.

Further information

There is a range of equipment and technology that can assist children with a physical disability to develop independent living skills. The Citizen Information Board has a website with information on such products <u>www.assistireland.ie</u>. Other information on accessibility is available at www.enableireland.ie.

You can find more information on services and benefits such as allowances, medical care, aids and appliances, tax credits and reliefs, travel and mobility and house adaptations from government departments. The following publication from the Citizen Information Board may be helpful: 'Entitlements for people with disabilities 2012' at: www.citizensinformationboard.ie/publications/providers/ downloads/entitlements_for_people_with_disabilities_2012. pdf.

Further information for parents/guardians can be found in the NCSE publications:

- Children with Special Educational Needs: Information
 Booklet for Parents
- Choosing a School: A Guide for Parents and Guardians of Children and Young People with Special Educational Needs
- Post-School Education and Training Information on Options for Adults and School Leavers with Disabilities

All available at www.ncse.ie

Useful contacts

Your local **SENO** may be contacted through the school or from the NCSE website at www.ncse.ie.

Department of Education and Skills: www.education.ie.

Local health centre: www.hse.ie.

Information about other supports to which you may be entitled are available on the website of **Citizens Information** at: <u>www.citizensinformation.ie</u> or from the relevant Government Departments.

Support organisations

AHEAD – Association for Higher Education Access & Disability: www.ahead.ie.

Central Remedial Clinic: www.crc.ie.

Citizens Information Board: www.citizensinformationboard.ie.

Enable Ireland: www.enableireland.ie.

Irish Kidney Association: www.ika.ie.

Irish Wheelchair Association: www.iwa.ie.

Multiple Sclerosis Society Ireland: www.ms-society.ie.

Muscular Dystrophy Ireland: www.mdi.ie.

National Parents Council Primary: www.npc.ie.

National Parents Council Post-Primary: www.npcpp.ie.

Neurological Alliance of Ireland: www.nai.ie.

Spina Bifida and Hydrocephalus Ireland: www.sbhi.ie.

Special Needs Parents Association: www.specialneedsparents.ie.

The Irish Epilepsy Association: www.epilepsy.ie.

Please note that this list is not exhaustive and these organisations are listed only for information purposes. The National Council for Special Education may have had no involvement with these organisations and cannot vouch for them or their staff. Parents should always satisfy themselves regarding the appropriateness of providing any information concerning their child to any third-party.



National Council for Special Education

1-2 Mill Street, Trim, Co. Meath. Tel: 046 948 6400 Web: www.ncse.ie Email: info@ncse.ie