

Information Pack: A Guide to Disability Law and Policy in Ireland

Inclusion Ireland

**- National Association for People with an
Intellectual Disability**



Updated: March 2014



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Introduction

Inclusion Ireland is the National Association for People with an Intellectual Disability and was founded in 1961 as namhi.

Inclusion Ireland is the largest national organisation working to promote the rights of people with an intellectual disability.

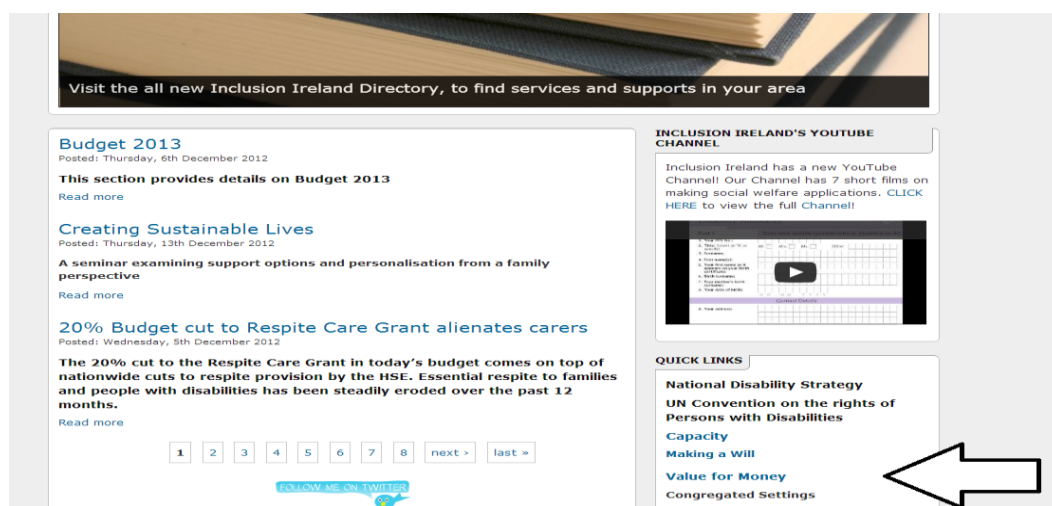
Our vision is that of people with an intellectual disability living and participating in their community with equal rights as citizens to live the life of their choice to their fullest potential.

How to use this guide:

Each of the sections of the guide is also a standalone factsheet. The factsheets are designed to be introductions to particular sections of law and policy that is relevant to disability in Ireland.

At the end of each factsheet you will see a link to our website where you can read more on the particular topic. Each factsheet will have a dedicated page on Inclusion Ireland's website www.inclusionireland.ie.

Each Section can be accessed through the 'Quicklinks' section on our homepage.



This information pack doesn't deal directly with rights and entitlements as there is an excellent resource by the Citizens Information Board on 'Entitlements for children with disabilities'¹ and 'Entitlements for people with disabilities'². It is available by calling 0761 07 4000 or at the links below.

¹www.citizensinformationboard.ie/publications/entitlements/downloads/children_with_disabilities.pdf
²www.citizensinformationboard.ie/publications/providers/downloads/entitlements_for_people_with_disabilities_2012.pdf

National Disability Strategy

 www.inclusionireland.ie/content/page/national-disability-strategy

The Government launched the National Disability Strategy in 2004 and looked to tie together law and policy in the area of disability. This was to include existing and future legislation.

The elements of the strategy are:

- The Disability Act 2005;
- The Citizens Information Act 2007;
- The Education for Persons with Special Educational Needs Act 2004;
- Sectoral Plans from 6 Government Departments;
- A multi-annual investment programme;

What is the Disability Act?

The Disability Act is a law brought in by the Department of Justice. The Act aimed to:

- Allow for an assessment of the needs of people with disabilities and a service statement;
- Improve access to public buildings, services and information;
- Ensure that certain Government Departments brought out Sectoral Plans outlining what improvements that department would take;
- Place an obligation on public bodies to be pro-active in employing people with disabilities;
- Restrict the use of information from genetic testing for employment, mortgage and insurance purposes;
- Establish a Centre for Excellence in Universal Design. The Centre would be charged with developing best practice guidance on how to design, build and manage buildings and spaces so that they can be readily accessed and used by everyone, regardless of age, size, ability or disability;

National Disability Strategy



Assessment of Need

The Act includes a statutory entitlement to an assessment of health and educational needs. Following the completion of an assessment of need a Service Statement is issued. This statement outlines the services that are proposed to be provided by the State. The statement does not set out what services are needed by the child, only what services are to be provided. There is also a complaints mechanism.

If they believe that their child has a disability, a parent or guardian may contact an assessment officer to apply for an assessment of need. You do not need a referral. Application forms are available at your local health office. The assessment must start within 3 months of the application. At present, an assessment is available to any child born after 1st June 2002, regardless of their age at the time of application.

You may make a complaint if:

- The Assessment Officer decides that your child does not meet the definition of disability;
- The assessment did not start within 3 months of an application being received, or took longer than 3 months to complete;
- You believe that the HIQA standards for assessment were not followed³;
- A service in the service statement has not been provided;

General complaints may be made to the Assessment Officer if it is about the assessment and to the Liaison Officer if it is about the Service Statement.

Formal complaints require that an application form is filled in and this is available from either officer. This form goes to the HSE.

If a parent is unhappy with how their complaint was handled they may appeal to the 'independent Appeals Officer'. Any decision of an Appeals Officer is binding and may only be appealed on a point of law.

Further information on assessment of need including details of Local Health Offices and a full list of Assessment Officers is available on

www.inclusionireland.ie/content/page/national-disability-strategy

³ The HIQA standards are available from www.dohc.ie or www.hiqa.ie

National Disability Strategy

Education for Persons with Special Educational Needs Act 2004 (EPSEN)

What is EPSEN?

All children have the right to primary education and children with special educational needs have a right to primary education until the age of 18. The EPSEN Act is currently on hold and the key sections that gave statutory rights to assessment, education plans and appeals processes for children with special educational needs have been deferred indefinitely.

EPSEN defines “Special educational need” as a “restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition”.

Under EPSEN, the following was envisioned as the system to assess children. However, **this system is not yet in place, and there is no date for its commencement:**

A child may be identified as having a special educational need if the principal of a school agrees that the child is not benefitting from the current curriculum. A principal may be notified by teachers in the school or parents of the child. The principal must take steps to support the child, and if this does not work then an assessment of the child should be carried out. This assessment should take place within 3 months and if the child is recognised as having a special educational need, EPSEN provides for the provision of an individual educational plan (IEP).

There are three types of education provision for children with special educational needs, **mainstream, special classes within mainstream and special schools.** EPSEN says that children should be educated in an inclusive setting unless this would not be in the best interests of the child or the effective provision of education for other children in mainstream education.

What is the National Council for Special Education (NCSE)?

The NCSE coordinates education services for persons with special educational needs through Special Educational Needs Organisers (SENOs). A full list of SENOs is available at http://www.ncse.ie/contact_us/SENO_List.asp.

The NCSE provides for resource teaching and special needs assistance supports to schools to meet the needs of children with special educational needs.

The NCSE also makes recommendations to the Department around applications for assistive technology, school transport and Home Tuition in respect of children with special educational needs.

National Disability Strategy

Citizens Information Act 2007 & The Personal Advocacy Service

The Citizens Information Act 2007 was included in the National Disability Strategy as the Comhairle Amendment Bill 2004. This law provides for the name change from Comhairle to the Citizens Information Board (CIB). The CIB is the statutory body which supports the provision of information, advice and advocacy on a broad range of public and social services.

The primary purpose of the Citizens Information Act 2007 is to provide for a legal right to advocacy and the establishment of a statutory advocacy service called the Personal Advocacy Service. The Personal Advocacy Service would have legal powers to enter premises and make enquiries on behalf of persons in residential and day services. Service providers would be legally obliged to co-operate with the service. Personal Advocates would have the power to pursue any right of review or appeal on behalf of the person with a disability. However, this statutory advocacy service is not yet in place, and there is no date for its commencement.

A National Advocacy Service was introduced by the CIB in 2011. This service replaced the 46 pilot advocacy projects, which were funded by the CIB between 2005 and 2010. The National Advocacy Service does not have statutory powers and service providers and other agencies have no legal obligation to co-operate with it.

The National Advocacy Service is organised and managed on a regional basis through the following five Citizens Information Services:

Dublin - covering the M50 area;

Northeast - Cavan, Fingal, Longford, Louth, Meath, Monaghan and Westmeath;

South East - Carlow, Kildare, Kilkenny, Laois, Offaly, Wexford and Wicklow;

Southwest - Cork, Kerry, Limerick, Tipperary and Waterford;

West - Clare, Donegal, Galway, Leitrim, Mayo, Roscommon and Sligo;

The National Advocacy Service can be contacted on the national phone number, 0761 07 3000

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UN Convention on the Rights of Persons with Disabilities

<http://www.inclusionireland.ie/content/page/uncrpd>

The UN Convention on the Rights of Persons with Disabilities (CRPD) is an international agreement that has been signed by Ireland. It is not yet a part of Irish law as Ireland needs to also ratify the agreement for it to have effect. The Government has said that one of the barriers to the ratification of the agreement is our current law governing decision-making (Lunacy Regulations Act 1871), and the Ward of Court System.

What does the CRPD cover?

The convention looks at the following areas:

- Equality and non-discrimination;
- Women and children with disabilities;
- Awareness raising and accessibility;
- Access to justice, liberty and security;
- Equal recognition before the law;
- Freedom from exploitation, abuse and cruel treatment;
- Freedom of movement;
- Living independently and community involvement;
- Personal mobility;
- Freedom of expression and opinion, and access to information;
- Respect for privacy;
- Respect for home and family;
- Education, health, rehabilitation, work and employment;
- Social protection;
- Participation in public, political, social and cultural life;

Equal Recognition (Article 12)

Article 12 has been referred to as the beating heart of the convention, and it refers to equal recognition before the law. This section affirms that persons with disabilities are entitled to enjoy legal capacity on an equal basis with others and that they should have access to the supports required to enjoy legal capacity.

Access to Justice (Article 13)

Article 13 states that persons with disabilities have the right to access to justice including as a witness. This includes the right to accommodations as required, and that training of relevant people should occur.

Living Independently (Article 19)

Article 19 states that persons with disabilities have the right to choose where they live and with whom they live. This article emphasises the importance of support to community living.

UN Convention on the Rights of Persons with Disabilities



Access to Information (Article 21)

Article 21 says state parties should take measures so that persons with disabilities receive information in a format accessible to them. State parties should urge private entities to make information accessible.

Respect for Privacy (Article 22)

Persons with disabilities should not have arbitrary or unlawful interference with their right to privacy including personal or health information.

Respect for Home and Family (Article 23)

This Article outlines the right of persons with disabilities to be free from discrimination around marriage, parenthood and relationships.

Education (Article 24)

The right of persons with disabilities to an education is affirmed in this article. State parties should ensure non-discrimination and equal participation. Persons with disabilities should not be excluded from the general education system on the basis of disability. The article also states the importance of life and social skills.

Health (Article 25)

This article outlines that there should not be any discrimination on the basis of disability. Health services that are required by a person with a disability should be provided as early as possible and should be local to their community.

Habilitation and Rehabilitation (Article 26)

State parties should ensure that persons with disabilities attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

Work (Article 27)

Persons with disabilities have a right to work and employment on an equal basis with others. States parties should promote work opportunities, public sector employment, vocational training and job retention programmes.

Social Protection (Article 28)

Persons with disabilities have a right to an adequate standard of living. Access to poverty reduction programmes should be made as should assistance with disability related expense.

Participation in Participation in Public, Political, Social & Cultural Life (Articles 28 & 29)

These Articles establish a person with disabilities' rights to vote and be elected, and participate in non-government organisations. Persons with disabilities have a right to access cultural life including television, theatres, museums and other leisure activities.

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Capacity

<http://www.inclusionireland.ie/content/page/capacity>



Ward of Court

Ward of Court is the only system of adult guardianship in Ireland. Ward of Court may also apply to children.

Under the Lunacy Regulation Act 1871 an application can be made to the High Court to find somebody incapable of managing their own affairs or property. If a person is found to be incapable of managing their own property then an order is made to make the person a Ward of Court.

Typically, the people who are subject to Wardship orders are people with intellectual disability, mental illness, Alzheimer's disease and dementia or brain injuries, and normally there is an amount of money concerned.

How are people made a Ward of Court?

There is no automatic procedure, an application has to be made by somebody. This may be a family member, a health worker, solicitor or another concerned person. An application must be accompanied by the statements of two doctors supporting the application.

The court will hold an inquiry and the person who is subject to the application must be notified, and may object, if they so wish. If the order is granted, a committee is established to manage the Ward's financial or personal affairs, or both.

What happens when a person is made a Ward of Court?

Wards are not permitted to make their own financial or medical decisions; instead the approval of the court is needed. A ward cannot travel without the permission of the court, nor can they make a will without permission. A Ward may not marry, but becoming a Ward does not invalidate an existing marriage.

Can a person be released from Ward of Court?

It is possible, but usual, for someone to be released (discharged) from Wardship. A person wishing to resume his/her own affairs would need to show evidence to the court of an improvement in their capacity to manage their own property.

Capacity

Voting

The right to vote

People with an intellectual disability have the same right as any other eligible person to vote.

Eligibility to vote

To be eligible to vote you must be at least 18 years-old on the day the Register of Electors comes into force **and** have been ordinarily resident in the year before the Register coming into force.

Register of Electors

The Register of Electors is the list of all person who are eligible to vote. Each local authority is responsible for compiling and publishing a list of eligible voters in its area.

Elections

Irish citizens on the Register of Electors can vote in General, Local and European elections and Constitutional Referendums. Information explaining the different types of elections is included in Inclusion Ireland Guide to Voting.

Where to Vote

Voting takes place in a Polling Station. This is usually in the local school or other public building. The person in charge of the Polling Station is called the Presiding Officer.

People may also be eligible for a postal vote if you have a of a physical illness or disability. You must be registered as a postal vote.

Electors with a physical disability can vote at an alternative polling station if their local station is inaccessible

Voters who live in hospitals, nursing homes or similar institutions and wish to vote at these locations, can apply to be on the special voters list.

Application forms for inclusion on the Electoral Register, Special Voters List and Postal Voters List are available from all local authorities, post offices and public libraries.

Capacity



Voters with an intellectual disability

There is no provision in law that treats voters with an intellectual disability any differently to other electors.

Voters with a physical disability, impaired vision or literacy difficulties

If an voter satisfies the Presiding Officer that their sight is so impaired, or that they are so physically incapacitated or that they are unable to read or write to such an extent that they are unable to vote without assistance, the voter may have his or her ballot paper marked either by a Companion or by the Presiding Officer.

The Companion must be aged 16 or over and can only assist up to two voters at an election. The Companion marks the ballot paper on behalf of the elector with a disability and places the paper in the ballot box.

Voters with a literacy difficulties can also have a Companion voter. For these voters, the Presiding Officer can assist the voter in marking his or her ballot paper. The Presiding Officer marks the paper according to the instructions of the voter.

Power to deny a voter assistance to vote

A Presiding Officer may, during the last two hours of polling, refuse an application by a voter to be assisted in filling in his or her ballot. This discretion, however, applies to the provision of assistance, rather than to the right to vote.

Further information

Inclusion Ireland has published a Guide to Voting which is available by contacting inclusion Ireland on 018559891 or email to info@inclusionireland.ie

Useful websites

A website where you can check if you're on the Register of Electors
<http://www.checktheregister.ie>

Inclusion Ireland accessible website
www.choices.inclusionireland.ie/

Inclusion Ireland's website
www.inclusionireland.ie

Capacity



Marriage

Requirements for Marriage

For a marriage to be legal the parties must;

- Have the capacity to marry;
- Freely consent to the marriage;
- Follow all necessary formalities;

Consent to Marriage

Consent must be free from duress (pressure) of any kind. If somebody consents to being married under threat or intimidation, then the marriage may be deemed void.

Consent may be said to be absent if one or both of the parties are intoxicated, mentally impaired or mentally ill, and therefore didn't understand the nature of the act of getting married.

Capacity to Marry

Unless the parties have the permission of a court, both parties in a marriage must be aged 18 or over.

A person lacks capacity to marry another if they are:

- Of the same gender;
- Already in a valid marriage;
- Related in blood to the other party;
- Lacking mental capacity;

Mental Capacity to Marry

Normally a person's capacity to marry is looked at in the event of a marriage breakdown. If the lack of capacity is found, then the marriage is void (annulled).

A person is said to have capacity to marry if they have an understanding of the nature and effect of getting married, meaning an understanding of the contract of marriage and its binding nature.

Before a marriage can occur, a marriage registration form will be issued by a registrar. To get this form, the registrar must be satisfied that both parties satisfy the criteria for marriage.

Wards of Court and Marriage

Wards of Court are not permitted to marry, but Wardship does not invalidate an existing marriage.

Capacity



Medical Decisions

Consenting to Medical Care

A medical decision cannot be made without the informed consent of the person who is being treated.

Exceptions include, emergency treatment to save the life of the person when the person cannot communicate (e.g. they are unconscious), and where the medical practitioner is acting under a court order (e.g. under a Ward of Court order).

A valid consent should be:

- Given freely and not under threats or inducements;
- Given when a patient has been given enough information in a way they can understand;
- The person understands the nature, purpose and likely effect of the treatment;

Capacity to Consent

Everybody should be presumed to have the capacity to make a medical decision.

This presumption can only be removed if there is clear evidence that the person is lacking capacity. A person does not lack capacity simply because of disability.

The Role of the Family in Medical Decisions concerning Adults

Family has no legal right to make decisions for any other adult whether that person has a disability or not.

The Irish Medical Council in their medical ethical guidelines will consult with parents or appropriate carers if they believe that capacity is absent.

There is no requirement for medical practitioners to follow instructions from family members, merely to consult with them.

Capacity



Sexual Relationships

Sexual relationships between adults are lawful as long as they are in consenting relationships. In order to consent a person must be over 17 years of age, or be married.

Sexual Offences and people with intellectual disabilities

There is a specific law dealing with sexual relationships and people with intellectual disabilities. The Criminal Law (Sexual Offences) Act 1993 makes it an offence to have, or attempt to have sexual intercourse with a mentally impaired person unless they are married to them.

A mentally impaired person is described as “a person suffering from a disorder of the mind, whether through mental disability or mental illness, which is of such a nature or degree as to render a person incapable of living an independent life, or of guarding themselves against serious exploitation”.

The legislation also does not apply where sexual intercourse occurs between married people.

Sexual acts short of sexual intercourse are not criminal offences under this section even if one of the parties is mentally impaired. Sexual acts other than intercourse are treated in the same manner as other sexual offences and generally the person alleging the assault is a key witness.

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Value for Money Report

www.inclusionireland.ie/content/page/value-money-review

This document is a Department of Health review on the Value for Money (VFM) and Policy Review of Disability Services Programme. The objectives of the review were to look at how effective and efficient the disability services funded by the Health Service Executive (HSE) are, and to review and make recommendations about policy in relation to services.

The review was looking at the Disability Services Programme and at all services, either directly provided by the HSE or by organisations with service level agreements with the HSE. The review provided a detailed report of how funding is used, but they found that quantifying the value for money aspect was difficult.

The overall tone of the report was that there should be a shift towards person-centered service provision with individually chosen supports, and that the process of funding places rather than people should be reversed.

There should be a more transparent assessment of need process with resource allocation based on need. The report also made clear that there were no additional resources available, and there was no lifting of the moratorium on recruitment.

The report made a number of recommendations around governance, administration and accountability. A full list of recommendations is available from the Department of Health website⁴.

Immediate actions to be taken:

- An examination of Service Level Agreements;
- A standard financial reporting mechanism developed and used;
- Every service provider to draw up a plan in line with VFM around staffing and costs;

⁴ http://www.dohc.ie/publications/pdf/VFM_Review_Recommendations_MasterList.pdf

Value for Money Report

What were the main recommendations?

- The current arrangement where block grants are given to service providers should be changed. A move should be made towards person-centered services with the active involvement of the individual. The allocation of resources should be based around individual need;
- The HSE should have a stronger national disability function and should be at the heart of decisions about funding, and shaping and driving the Disability Services Programme. There is currently no direction on resources from the HSE;
- Standardise financial reporting so that expenditure can be tracked and monitored;
- A model should be designed so that resources are allocated in a transparent and effective manner, based on an appropriate assessment of need and protocols for resource allocation;
- Pay caps should be put in place, particularly for CEOs. The CEO will also be responsible for driving and reporting on efficiencies;
- Non-professionally qualified staff should be replaced by professionally qualified staff;
- Sharing of services between agencies should be explored and facilitated;
- Alternative forms of respite should be looked at, in particular community based forms such as 'share a break' with a host family in the community;
- Individuals should be able to request a review of the supports that they are receiving and a lifecycle approach to supports should be taken;
- A framework for determining the quality of services should be developed;

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Congregated Settings Report

www.inclusionireland.ie/content/page/congregated-settings

The report prepared by the HSE titled *Time to move on from Congregated Setting: a strategy for Community Inclusion* was published in June 2011. A working group was established in 2007 to put the report together.

The report outlined how people who live in congregated settings⁵ should move into community living. There are more than 4,000 people living in a congregated setting at present in Ireland.

The vision of the working group was that people with disabilities in congregated settings will be “actively and effectively supported to live full, inclusive lives at the heart of family, community and society. They should be able to exercise meaningful choice, equal to that of other citizens, when choosing where and with whom they will live”.

The working group concluded that community living offered the prospect of an improved lifestyle over institutional care and that it was no more expensive to provide. The requirement of adequate support was highlighted by the report as crucial.

The Report said the Department of Health should make clear the following:

- All people living in congregated setting should move to the community;
- There should be no more congregated settings opened;
- There should be no more admissions to existing congregated settings;
- A 7-year target should be set for moving people from congregated settings, into a community setting;

The Report also stated that the National Housing Strategy⁶ should reflect the findings of this working group, and should describe the eligibility of people with disabilities for publicly funded housing supports.

There were 31 recommendations, which are set out over the next two pages:

- A senior official from the HSE should be given a national brief to oversee the implementation of the recommendations in this report as well as a National Implementation Group;
- The National Implementation Group should look at the human resource requirements and plan for this;
- A working group should be established to set up protocols across all key government departments - these protocols should be consistent with the National Disability Strategy and Sectoral Plans;

⁵ Settings where ten or more people with disabilities were living

⁶ See Factsheet on National Housing Strategy


Congregated Settings Report



- A programme should be set up in order to manage the change and transition among staff, families and people with disabilities;
- A model should be designed for movement to community settings that goes beyond an examination of accommodation. A person-centered approach should be at the heart of the model;
- People should move to dispersed housing⁷ where they may desire;
- People should be able to choose to live on their own;
- People should be able to share with others who do not have a disability;
- People should be able to share their home with other people with a disability;
- People should be able to live with their own family, or opt for long-term placement with another family;
- Where home-sharing is a chosen option, there should be no more than four residents, all of whom have chosen, as far as possible, to live together. Support should be put in place that is of the individual's own choosing. These supports may be combined with others if appropriate and controlled and managed by the individual;
- Programmes must be developed around advocacy, person-centeredness, community inclusion, in-home support, work & employment, community based primary care and specialist support;
- The Department of Environment should be responsible for housing, but the HSE should be responsible for putting supports in place for living in the community;
- Supports that the individual needs in their own home should be looked at and delivered separately to supports needed for community inclusion;
- A structure in the local HSE area should ensure that these supports are co-ordinated;
- Service level agreements should exist between the HSE and service providers, and an examination of ways of introducing individualised budgets should be carried out;
- The funding currently in place for congregated settings should be retained but redirected towards supporting community inclusion;
- Accommodation needs for people who are leaving a congregated setting should be met through a combination of purchased housing, new-build housing, leased housing or rented housing;

⁷ Apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population

Congregated Settings Report

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- Newly built accommodation may be necessary in some instances. Where possible providers of congregated setting residences may sell land or receive a loan from the government to facilitate new builds;
 - All those making the transition from congregated settings should be assessed for eligibility for Rent Supplement or Rental Accommodation Scheme. Government Departments need to examine and clarify this issue;
 - Local authorities, service providers and the HSE should put together a re-housing plan. All residents should be assessed to establish eligibility and need for social housing support;
 - Local authorities should reserve a certain proportion of homes for people with disabilities;
 - A 7 year timeframe for closure of congregated setting should be set with annual targets;
 - An implementation team with a named responsible person should be established with responsibility for readying local public and voluntary services;
 - All agencies operating congregated settings should produce and submit a transitional strategy to the HSE. These strategies should form part of the service agreement;
 - Facilities called *Accelerated Learning Sites* should be set up to implement the recommendations and to look at examples of community based living models;
 - A congregated settings fund should be set up;
 - An evaluation framework should be set up to ensure consistency of approach and to underline any new projects;
 - Resources should be made available to people with disabilities, families, and staff to transfer to the community and to develop community readiness;
 - Advocacy provision is important during the transition process;
 - The group also identified that there are congregated settings outside of their scope that needed to be looked at, including people inappropriately placed in nursing homes and people with disabilities in mental health settings;

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National Housing Strategy

www.inclusionireland.ie/content/page/national-housing-strategy

What is the National Housing Strategy?

The *National Housing Strategy for People with a Disability 2011-2016* examines the area of housing and people with disabilities. It looks at establishing a framework for the delivery of housing for people with disabilities through mainstream housing policy. The Strategy was developed by the Department of Environment, Community and Local Government, and launched in October 2011.

What is the Vision of the Strategy?

The stated vision of the strategy is:

To facilitate access, for people with disabilities, to the appropriate range of housing and related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living.

What are the aims of the Strategy?

The Strategy aims to do nine things:

- Promotion of equality of access - equal access for people with a disability to all housing options available, depending on the individual or household needs. An assessment of need for people with disabilities will be carried out. Housing authorities will be required to preserve a proportion of housing that meets particular needs;
- Promotion of interagency cooperation - meaning that environment, housing, health and other services and supports would work together;
- Put supports in place to allow people with disabilities to live independently - priority is to be given to the adaptation grant schemes, and a policy of 'universal design'⁸ is to be promoted in the long term;
- Address the specific housing needs of people living in congregated settings⁹;
- Address the specific housing needs of people with an illness - people with low and medium support needs should move from HSE services to community settings through cooperation between the Department of Environment,

⁸ The design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people, regardless of their age, size or disability (Centre for Excellence in Universal Design)

⁹ See Factsheet on Congregated Settings

National Housing Strategy

Community and Local Government, the Department of Health, local authorities and the HSE;



- Policy and practice in relation to the design and delivery of housing supports should be examined. These policies and practices should be based on a variety of approaches and a pilot will be developed to test good practice. This pilot will look at housing design, person-centeredness and interagency cooperation;
- Appropriate advice and information should be available to people with disabilities in relation to their housing needs. Literature should be made in a variety of accessible formats and a pilot *housing advice centre* considered;
- Improve policy development and service delivery by improving data collection - the assessment of need process carried out by local authorities will assist this process;
- A group will be set up, chaired by the Department of Environment. This group will set up an implementation plan in order to progress the strategy. The group will also look at ways to identify sustainable funding;

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Standards

www.inclusionireland.ie/content/page/standards

Background

The Health Information and Quality Authority was established in 2007 as an independent body charged with the quality and safety of healthcare services. Part of their remit is to develop standards, monitor compliance and investigate. Standards were developed for children and older people and in 2009 HIQA published a set of standards for persons with disabilities in residential settings. Inspection on the standards was postponed owing to a lack of resources, and a revision of the standards was subsequently announced.

In May 2013 HIQA formally launched the National Standards for Residential Services for Children and Adults with Disabilities. Registration of services is due to begin in September 2013, which is the first step towards inspection of services.

An approved residential centre will have to undergo inspection and meet the requirements set out in these standards. In the past, HIQA have closed residential centres for older people that did not meet required standards.

What do the Children Standards Say?

There are 8 themes:

Child Centered Services: The rights of children under the UN Convention on the Rights of Persons with Disabilities (CRPD)¹⁰ should be respected and children supported to exercise those rights. Appropriate boundaries should be kept and privacy maintained. Children are given choice in a wide range of areas including daily routine, dietary, access to pocket money and that age appropriate risks are taken. Links to the community, including family and friends, are maintained and that families are involved in the child's care unless this is not appropriate. Children have access to accessible and age appropriate material, including the standards. Children have an opportunity to contribute to decisions, give consent where legally required (e.g. medical treatment), and have access to an advocate. Complaints and concerns are listened to and responded to, and the child has access to an advocate.

Effective Services: Each child as a personal plan, which they are involved in planning, and hold a copy of the plan. The plan is reviewed annually. The residential home is homely, accessible and allows for privacy and safety. Written policies on admission and discharge are put together. Children are helped to prepare for adulthood with life skills training, and an account is taken of training or employment needs. Service providers providing respite should follow the standards.

¹⁰ See Factsheet on the CRPD

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Safe Services: Children are protected from abuse or neglect with clearly defined procedures for intimate care and complaints. Children should be given education on protection and safety. Emotional, behavioural and therapeutic support is provided to each child. Restrictive behaviour is to be avoided unless deemed necessary and an emergency, in accordance with a procedure, and monitored and reviewed. A policy and review of adverse events is in place.

Health and Development: The health and development of children is improved and children are consulted about this process. A health assessment is carried out and necessary supports are put in place. A procedure is put in place for medication management. Only qualified staff may dispense medication. Educational opportunities are maximised, including continuity of schooling, needs assessment and examination of progression opportunities, including third level.

Leadership, Governance and Management: Relevant legislation, regulations, policies and standards are followed, and are known by all staff in a residential setting. A clear line of leadership and accountability must be established with strategic and operational plans. The service should design a "statement of purpose", which is publicly available. The service should have a current and appropriate service level agreement with its funders.

Use of Resources: Use of funding should be planned and used transparently. Better ways of using funding should be regularly introduced.

Workforce: Relevant legislation is followed in recruitment and Garda vetting, and reference checks carried out. There are sufficient staff numbers in place and staff members are sufficiently qualified. Staff supports and supervision should be put in place and appropriate staff training made available.

Use of Information: Information should be used in accordance with the law, ethically and stored securely. Information sharing is important to ensure effective service provision, but only in accordance with the law.

Standards



What do the Adult Standards Say?

There are 8 themes:

Person-Centered Service: The rights of people with disabilities under the UN Convention on the Rights of Persons with Disabilities (CRPD) should be respected. People should be informed of their rights and supported to understand and exercise those rights. Dignity, privacy, respect and equality of the person is promoted at all times. People should be given choice and control in their own daily life including diet, social, cultural and religious requirements. Residents have an opportunity to contribute to the planning of the service. Personal relationships are encouraged and promoted, including family and friends and members of the community. Information that is given to people with disabilities should be provided in a way accessible to them and support should be given to access information. The legal capacity of each individual on an equal basis with others should be recognised. Complaints are listened to and individuals are given access to an advocate.

Effective Services: Personal plans are drawn up with involvement from the person and their families. Plans should encompass health, social, educational and employment wishes, and supports that are needed. People should have a copy of their plan in an accessible format. The residential home is homely, accessible and allows for privacy and safety. Written policies on admission and discharge are put together. Young adults are supported in their transition to adult services. Service providers providing respite should follow the standards.

Safe Services: Individuals are protected from abuse or neglect with clearly defined procedures for intimate care and complaints. Individuals control their own money unless they wish to nominate another person to. Where financial abuse is suspected, advocates and legal advice is made available. Emotional, behavioural and therapeutic support is provided where appropriate. Restrictive behaviour is to be avoided unless deemed necessary and an emergency, in accordance with a procedure, and monitored and reviewed. A policy and review of adverse events is in place.

Standards



Health and Development: Health and development is promoted and cooperation with other agencies and non-state provided agencies occurs. Information on diet and nutrition, recreation, smoking/alcohol/drug education, exercise and sexual relationships/health should be provided. Health assessments are carried out including mental assessments and GPs are available. Only qualified staff may dispense medication and individuals should manage their own medication if they wish. Education, training and employment opportunities should be made available to individuals.

Leadership, Governance and Management: Relevant legislation, regulations, policies and standards are followed and are known by all staff in a residential setting. A clear line of leadership and accountability must be established with strategic and operational plans. The service should design a “statement of purpose”, which is publicly available. The service should have a current and appropriate service level agreement with its funders.

Use of resources: Use of funding should be planned and used transparently. Better ways of using funding should be regularly introduced.

Workforce: Relevant legislation is followed in recruitment and Garda vetting and reference checks carried out. There are sufficient staff numbers in place and staff members are sufficiently qualified. Staff supports and supervision should be put in place and appropriate staff training made available.

Use of Information: Information should be used in accordance with the law, ethically and stored securely. Information sharing is important to ensure effective service provision but only in accordance with the law.

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New Directions Report

www.inclusionireland.ie/content/page/new-directions

What is the New Directions Report?

The New Directions report was published in February 2012 and set out a proposed new approach to adult day services for people with disabilities. This new approach involves delivering 12 supports, which are collectively called *New Directions*.

A National Working Group was established to look at day services. In addition to looking at Irish and international practices, they conducted a census of day service users and a consultation with stakeholders. The review concluded that there was some confusion around what constituted a day service, and that what was happening on the ground was diverse and varied.

What did the Report say?

The report raised a number of areas of concern:

- There is a large number of over 65s in receipt of a day service which the working group considered an indicator of a lack of opportunities for progression;
- There are a number of service users in work-related activities, and their legal status may border on that of an employee. This was identified as an area in need of urgent clarification. The HSE should no longer offer sheltered or supported employment;
- There was variance in people's experiences of day service. While some service users reflected a worthwhile experience, there was a common theme of a lack of choice, repetitive activities or time spent doing nothing. This highlighted the need for a quality assurance system;

The report also highlighted what all the stakeholders had said:

- The people with disabilities who took part in the census said that they wanted to be able to do "ordinary things...in the community";
- People with disabilities said they wanted better information and to be able to move between services – services should be "joined-up";
- Service providers who were consulted said that they needed appropriate funding, transport provision and adequate staffing levels;
- Service providers wanted quality standards based on person centered principles;

New Directions Report

What are the Supports that make up “New Directions”?

1. Support for making choices and plans;
2. Support for making transitions and progression;
3. Support for inclusion in one’s local community;
4. Support for accessing education and formal learning;
5. Support for maximising independence;
6. Support for personal and social development;
7. Support for health and wellbeing;
8. Support for accessing bridging programmes to vocational training;
9. Support for accessing vocational training and work opportunities;
10. Support for personal expression and creativity;
11. Support for having meaningful social roles;
12. Support for influencing service policy and practice;

The supports should equip people with disabilities to make their own choices and set goals and to achieve those goals, to have influence over decisions that affect them and to be active and independent members of society.

How will “New Directions” be implemented?

- **Service Providers** will need to reform governance, policies, programmes and practices to reflect person-centeredness;
- The **National Disability Strategy** will need to be accelerated, in particular is mainstreaming element;
- The **HSE** should establish a “change management plan”, including strategies for promotion and evaluation of New Directions;
- The **HSE** should complete and roll out the Quality Assurance System;

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Financial Matters

www.inclusionireland.ie/content/page/making-will

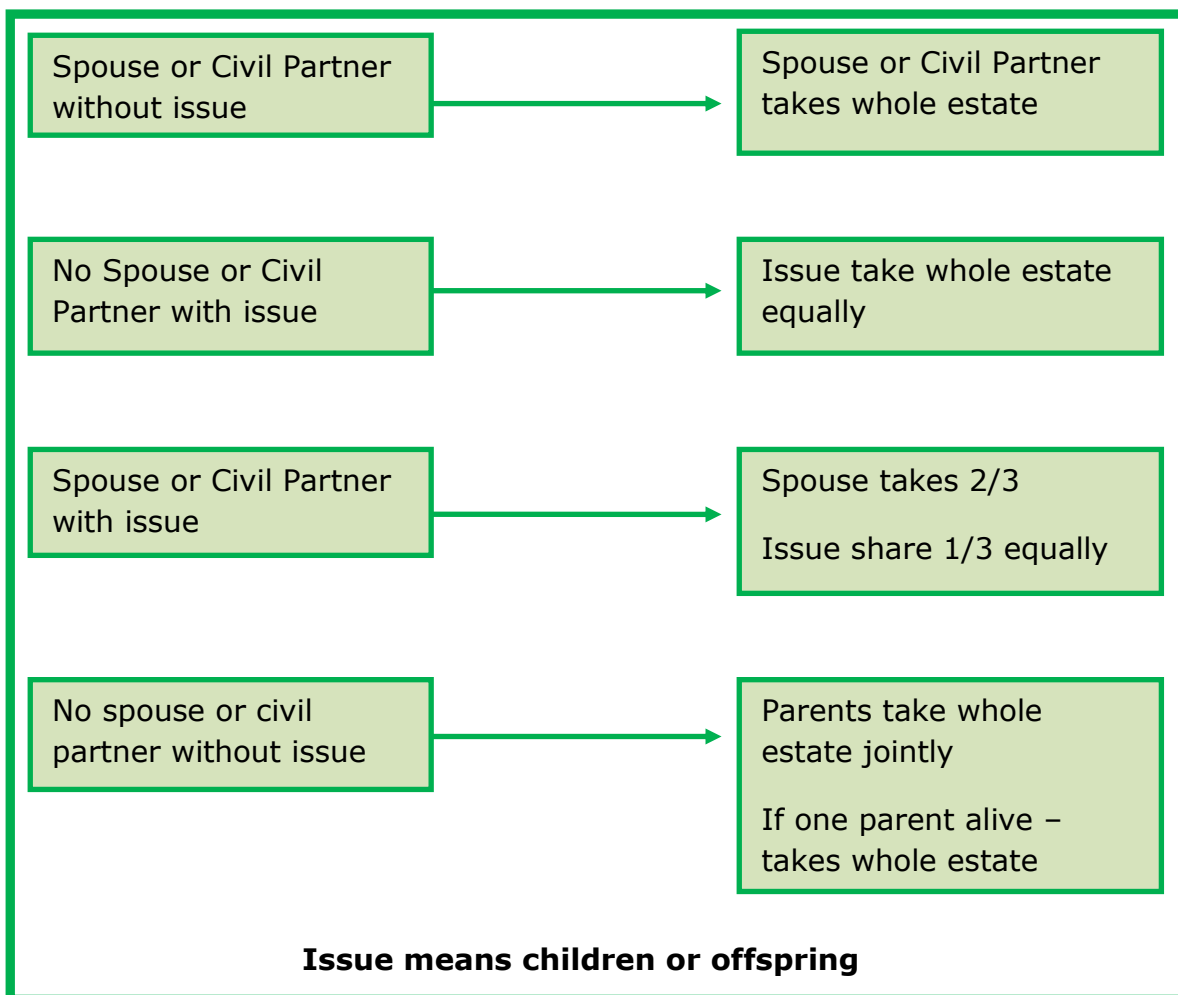
Wills

Making a will is a very important process for anybody who owns property or assets. Many parents of a person with an intellectual disability are especially concerned about making proper provision for the future. It is important to make a will as soon as possible, as dying intestate (without a will) can create complications with surviving spouses and children receiving different amounts. It is always worth remembering that changes to a will can always be made through a codicil, which is a device used to change parts of a will.

Do I need a solicitor?

It is usual to involve a solicitor. A solicitor is especially recommended if you are looking to set up a trust fund as the legal accuracy is very important. If a will is made up incorrectly, or is not valid, then the rules of intestacy kick in and the property is shared out among surviving relatives.

What is Intestacy?





Discretionary Trusts

What is a valid will?

In order to make a valid will, the following criteria must be satisfied:

- The will is in writing;
- The will is made voluntarily without pressure from other people;
- The person making the will is of sound mind;
- The person making the will is over 18 or has been married;
- The will must be signed at the foot of the will and witnessed;
- The witnesses or their spouses must not benefit from the will;

What is "Sound Mind"?

This means that you have the mental capacity to make a will and understand that you are making a will.

Do I have to leave my property to my children equally?

No, you do not have to leave property to your children equally. However a child, (under or over 18), may bring an application under the Succession Act that proper provision has not been made for them under the will. The court will look at the child's position in life, as well as any payments made to them during the lifetime of the testator.

Should I make particular arrangements for my son or daughter with an intellectual disability?

Careful consideration should be taken when leaving property to a person with an intellectual disability. While many parents wish to plan for the future, it is worth remembering the means test for any state benefits being received. A person's payment from the Department of Social Protection may be impacted on if they inherit a certain amount¹¹. Parents should also be aware that some people with an intellectual disability have been made a Ward of Court following significant inheritances. This may occur where somebody becomes concerned about a person's ability to manage their own financial affairs.

Some people have used trust funds when benefiting their son or daughter in a will. Generally speaking the capital in a trust fund will not interfere with state benefits, and irregular or once off payments from the trust are also generally not assessed as means.

However, regular maintenance payments would be considered as cash income and be assessed as means. Advice should be sought from the Department of Social and Family Affairs for the latest information.

¹¹ <http://www.inclusionireland.ie/content/page/making-will>



Discretionary Trusts

Many parents look towards setting up a trust fund, and often use a discretionary trust. There are many trust fund types available and a discretionary trust is only one to consider.

In a discretionary trust, the trustees have discretion over when and how much they give to the beneficiary. It is important that trustees are people who you trust, and although it is up to the trustees to make decisions about the trust, you may leave a 'letter of wishes' to guide the trustees.

A Discretionary Trust;

- Is a way of indirectly benefitting a person;
- The person setting up a trust is called a Settlor;
- The Settlor can set up a trust while alive, or through a will;
- Where the trust states that it is exclusively for the benefit of an incapacitated person there is an exemption of the tax levies;
- The assets in the trust are not considered for means testing of Disability Allowance;
- Two or more people called trustees are named to decide how the assets in the trust are used;
- As the name suggests the trustees have complete discretion as to how the assets are used;

Who can be a trustee?

A trustee could be someone in your family, a friend or a professional person such as a solicitor or accountant. Careful thought should be given to the number of trustees. It is often a good idea to have three trustees, as where there are two trustees, there is a chance that a disagreement could occur over how to use the money. The age of the trustees is important too, as it is desirable that the trustee outlives the beneficiary.

Are there Tax implications when making a will/trust fund?

There are always tax implications when inheritance is involved, and the Revenue Commissioners should be consulted when drawing up a will.

Progressing Disability Services for Children & Young People

www.inclusionireland.ie/content/page/progressing-disabilities-services-children

Historically in Ireland, services for children with a disability have developed in an uncoordinated manner, meaning that services varied greatly depending on where you lived and the nature of the child's disability. As a consequence, many parents are unable to access a suitable service for their child.

To ensure a more equitable access to disability services for children, a national program has been set up to reconfigure how disability services are delivered in Ireland. This program takes its lead from the *Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18*, which was published in 2009.

The broad aims of the program are:

- To have one clear pathway to services for all children with a disability in any given locality, regardless of the nature of their disability;
- There will be a uniform and clear referral method for parents and professionals;
- Services will be restructured. A service will be delivered by an early intervention team, or by a team for school age children (up to 18 years), regardless of diagnosis;
- Through local service provision, no child should be left without a service;
- Depending on the complexity of the child's needs, they may be seen by a local primary care team, a children's network disability team or children's specialist disability service team;
- Health and Education services must work together to support children to achieve their potential;

It is envisaged each child will undergo an assessment by a multidisciplinary team to determine the level of support they may need.

There is acknowledgement that we are now living in a time of limited financial resources but that services must live within budget, and use their resources to achieve maximum benefit for children and families.

Progressing Disability Services for Children & Young People



How will services be delivered?

Primary care teams: It is envisaged that the majority of children with less complex needs will have their needs met by their local primary care team. A typical primary care team may include the following professionals: general practitioners, nurses, physiotherapists, occupational therapists, social workers, speech and language therapists and clinical psychologists.

Network disability teams: Under the new model, network disability teams will have the experience and skills to deal with a range of disabilities including intellectual disability, sensory disability, physical disability and autism. A typical network disability team should include professionals such as physiotherapists, speech and language therapists, occupational therapists, social workers, clinical psychologists, paediatrician (sessional), key worker, family support workers and therapy assistants. These teams may also have the support of a dietician and orthotist when needed.

Specialist disability team: These teams will be provided at a regional level and specialise in each of sensory disability, intellectual disability, physical disability and autism as required. These teams will provide direct service to children with complex needs on a short term basis, and consultancy to clinicians in primary and network disability teams.

Parents are to be consulted during the change process.

Although, an assessment is envisaged for each child to determine the level of service they require, as yet no access criteria exist.

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Acknowledgements



Inclusion Ireland would like to acknowledge the contribution of Seàn Andrews, Mary Dunne, Jacinta Walsh from Autism Support Louth/IAA and Mairead Mekki, all of whom read this document and gave feedback on its contents.

Inclusion Ireland would also like to acknowledge the contribution of Fiona O'Sullivan, Solicitor with Woulfe Murphy Solicitors, Limerick and to the Public Interest Law Alliance (PILA).