

# **WHAT NOW... WHERE NEXT?**

## **PART D**

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### **RIGHTS**

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# RIGHTS

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## 1. INTRODUCTION

The term 'rights' can be very difficult to come to grips with. On the one hand it is used by people looking for political freedom and on the other hand can be used by those seeking something like an education. So what does the term mean for a person with disabilities and his/her family? It might help if we discuss the term 'rights equality'. For people with disabilities what is important is that they have the same rights as all other people in society.

That's what 'rights equality' means. However, because people with disabilities, in particular, those with intellectual disabilities and/or autism, have difficulty in speaking up for themselves, they very often do not get treated equally. What this means is that they may not get the same access to health care, education or other public services and infrastructures. This includes the services and supports essential to their lives (See also Part B on Assessment).

Over the decades, society has moved to recognise that some groups need to be assisted in accessing their rights. The result of this is that we have a blinding array of organisations and bodies that have concerned themselves with the issue of rights.

Internationally, we have the UN, the EU, International Courts and other organisations. Nationally, the State is charged with protecting the rights of the citizen through the constitution, legislation and the courts. We also have other organisations and bodies such as the Irish Human Rights Commission and Ombudsmen. With all of

these bodies talking about rights and the protection of the citizen, it can get very confusing.

In this section we will try to explain 'rights'. We will then try to outline some of the important aspects of rights and equality as it affects people with intellectual disabilities and/or autism and their families. We will not attempt to deal with the complex detail of constitutional provisions or the law. We'll leave that to the better qualified in the offices of the organisations mentioned above.

## 2. WHAT ARE OUR HUMAN RIGHTS?

Typically rights are categorised into two groups:

### **Civil and Political**

This includes the right to express yourself freely, the right of free assembly, protection from discrimination, freedom of conscience and the right to vote.

### **Economic, Social and Cultural**

This includes the right to own property, the right to economic security, the right to social and cultural security (including healthcare, education and a secure place to live).

People with intellectual disabilities often do not have the facility, or they are not facilitated in, the exercise of their Civil and Political rights. For example, some people find it difficult to exercise their right to vote. As a result, they don't have the power to directly influence society's leaders.

They are also unable, or find it difficult, to secure their Economic, Social and Cultural rights. For example, it would be very difficult for a person with an intellectual disability to go to a TD's clinic to try and secure the speech and language services they require. Instead they have to rely on others to do this for them.

In any case, people with intellectual disabilities and/or autism face other near insurmountable barriers to securing their Economic, Social and Cultural rights (even if they could go to the TD's clinic). They face the barriers of ignorance, neglect and stigmatisation.

The basic principle here is that, no matter what their circumstance, all citizens should have equal rights. Not more, not less, equal.

At times you may hear the criticism or comment expressed in questions like

*“why should the State pay for your son/daughter or family member to have ‘such and such’ when I have to pay for it myself?”*

The simple answer lies in the fact that in our constitution and because, as a State, we have signed up to international treaties on human rights. We, the people of Ireland, have accepted that all people should have equal access to human rights. Consequently, we, the people of Ireland, have accepted that if a person, through no fault of their own, has a difficulty accessing their rights then all others in society will assist them in so doing. In simple terms, we have accepted that we have an obligation to help each other. If everyone accepts this obligation why do we need laws and international treaties concerning human rights? The reason is that not all countries and not all people uphold this principle of helping each other.

When people don't accept the principle of helping each other it is called an 'abuse of human rights'. Unfortunately, for people with disabilities and others in Irish society, such abuses have occurred and still do to varying degrees.

### 3. WHAT CAN HELP PEOPLE TO ACCESS EQUAL RIGHTS?

#### *The Constitution*

The Irish Constitution provides for many rights for Irish citizens including:

- Freedom of association
- The right to an education
- The right to life
- Religious liberty
- The right to trial by jury
- The rights of the family
- The right to bodily integrity
- Property rights
- Freedom to travel
- The right to earn a livelihood
- Personal liberty
- Inviolability of dwelling
- Freedom of expression
- The right to fair procedures
- Freedom of assembly
- The right to privacy

As citizens, people with intellectual disabilities and/or autism are equally entitled to the above rights under the constitution. The Dáil is charged with the governance of the State and, in this, must uphold the constitution. Furthermore, the courts are charged with the protection of citizens' rights under the constitution. However, there's a catch. The Dáil is also obliged to have regard to the resources of the State. That is, the Dáil must look after our finances. Therefore, in ensuring citizens'

rights, the Dáil is restricted by the availability of resources. In other words, it cannot spend what it does not have.

How then can the Dáil fulfil its obligation to treat all citizens equally? The Dáil cannot spend more resources on one sector of society while leaving another sector with insufficient resources. Getting this right is a difficult balancing act and is crucially important for people with intellectual disabilities and/or autism. In this, advocacy and helping people with disabilities to be heard equally, is crucial.

### ***Disability Legislation***

There are two important pieces of legislation dealing with disability: The Disability Act 2005 and the EPSEN Act.

***The Disability Act*** deals with issues such as physical access, the response of the State organisations and bodies to people with disabilities and crucially the right to an ‘Assessment of Needs’. As covered in Part B, this right, while crucially important, is only a right to an assessment and not a right to services or supports (see NOTE below). The provision of services and supports is constrained in the legislation by the availability of resources and only if the provision of the service or support is ‘practicable’. What this means is that the State has no absolute obligation to provide the services or supports identified in the assessment of need.

NOTE: There are some that would argue that the “right” to an assessment isn’t a right at all. Those people argue that it is also subject to resources.

A further difficulty is that the ‘assessment’ process has, as yet, been rolled out only for children who were under the age of five as on June

2007. The State is currently having a lot of difficulty progressing the assessment process.

Even with its shortcomings this piece of legislation is very important. It can be used to help in supporting people with disabilities as it establishes a “right” to an assessment of need and even if constrained as detailed above, it nevertheless, acknowledges that the State has particular obligations towards people with disabilities.

***The EPSEN Act*** deals with the special education needs of children and young people with disabilities. Part E deals with some provisions of the act in more detail. In short, the EPSEN Act provides for an assessment of education needs and the drawing up of an ‘Individual Education Plan’ and other provisions. However, much of it has not yet been rolled out.

Further, in terms of rights, the act is once again constrained by available resources and does not bestow an absolute right to particular supports in education. Nonetheless, like the Disability Act, it does provide legislative support for people with intellectual disabilities and/or autism in receiving an education more suited to their needs. It must be said that, at times, the quality and appropriateness of State support is seriously questioned by parents.

### ***Other Legislation***

Other general pieces of legislation have relevance such as the Health Acts and general Education Acts. In particular, the collective Health Acts, The Mental Health Act, 2001 and The Child Care Act,

1991, all impose a **duty of care** on the HSE to provide for the health and welfare of all persons in their respective catchments. However, allied with this the Public Sector Employment Act, 1997, imposes a responsibility on the HSE not to overspend its allocated annual budget. As the HSE never has sufficient funds to meet the health and welfare needs of everyone to the level they want, families have to fight to have their child's (or other family member's) needs prioritised in budget allocations by the HSE. In practice, families have to lobby for such resource allocations individually and collectively through parent and support groups.

Forcing the HSE to recognise that they have a legal duty of care, however, is a powerful tool and has been used successfully by families in bringing legal cases against the HSE and the State:

**Excerpt from *The Irish Times*, Home News, 17<sup>th</sup> October, 2002:**

***“Court Hears of Care Plan for Autistic Man***

*The High Court has heard a care plan has now been agreed for a 21-year-old man who is autistic and epileptic. He had sued the State and a health board (HSE) seeking adequate care and education. The plan relates to the man's present and future position; issues relating to past care remain outstanding. The document covers residential, medical, educational and general care. The action was taken by Mr Adrian James Cronin, of Cregg House, Rosses Point, Sligo. The proceedings were against the Minister for Education, Minister for Health and Children, the North Western Health Board, Ireland and the Attorney General. Yesterday, Mr Justice White was told terms had been agreed between the sides. He adjourned the case generally pending the implementation of the care plan. It was claimed on behalf of Mr. Cronin that he was owed a duty of care by the defendants in the exercise of their constitutional and statutory*

*obligations and that they had failed to comply with those obligations. The defendants had failed to provide for his education needs to date and had also failed to properly provide suitable and proper health care facilities for him, it was submitted”.*

The case did not go to judgement. These cases rarely do, as the Government fear that if they did, judgement would be found against them. This would force the State, when seeking to balance their budgets, to prioritise certain services and supports above others.

***International Treaties, Organisations and Obligations***

There are many international treaties and organisations that are relevant to the rights of people with disabilities, for example: International Courts, the UN, the EU and its courts (particularly the European Court of Human Rights) and others. It is beyond the scope of this booklet to try to cover them all. Instead we will concentrate on the one that is most relevant:

**UN Convention on the Rights of Persons with Disabilities**

UN conventions by their nature are based on establishing a set of principles. This convention established the following principles in respect of persons with disabilities:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- b. Non-discrimination;

- c. Full and effective participation and inclusion in society;
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e. Equality of opportunity;
- f. Accessibility;
- g. Equality between men and women;
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The convention then goes on to set out the obligations on countries signing the treaty. These obligations are binding and detailed (for a full copy of the Convention see <http://www.un.org/disabilities/convention/conventionfull.shtml>).

In essence, the obligations spell out what the State must do to comply with the convention. The following are extracts from some of the ‘general’ obligations:

*“States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake: (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention; (b), (c), (d) ...”*

And:

*“With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights...”*

Note from the second extract that the obligation is subject to available resources and envisages the ‘progressive’ realisation of the rights as set out. Progressive Realisation means that there will be gradual improvement in the person’s situation and eventually he/she will get full rights. This recognises that States have varying resources available and will not necessarily be able to achieve everything immediately.

There are additional ‘general’ obligations and many further ‘detailed’ obligations covering areas such as health, education, employment, security etc. The subject matter of the most pertinent detailed obligations are listed in Appendix B at the end of this Part.

The UN Convention is a very important one for people with disabilities and their families. Ireland signed up to the Convention on 30 March 2007 but unfortunately we have not as yet ‘ratified’. Ratification means giving the Convention legal status. The delay is primarily to do with the fact that we do not have other required pieces of legislation in place; most particularly what is called ‘Legal Capacity’ legislation (see Legal Capacity legislation below). Nevertheless, it is expected that Ireland will ratify in the near future. What this will mean is that we, as a country, will be obliged to put in place facilities, legislation and otherwise, to allow people with disabilities access their human rights and, importantly, to remove any barriers that might currently exist. This will provide people with disabilities and their families with a powerful tool

to compel the State and all State bodies, departments and organisations, to do all that is possible, subject to available resources, to ensure the rights of people with disabilities are upheld equally with all other citizens. However, it is worth keeping in mind that the State will be expected to progressively realise people's rights. In other words, it will probably happen gradually.

#### **4. SOME IMPORTANT ASPECTS FOR FAMILIES AS CARERS OF ADULTS**

##### **When Children Become Adults**

Under the Irish constitution there is a stated principle that married parents have equal rights to their children and are joint guardians of their children. If parents separate or divorce, the courts may decide who will have custody of the children. The paramount consideration is the welfare of the children.

Parents, as guardians of their children, have rights and obligations. They have the right to direct their children. They have a direct legal say in what happens to their children. For example, parents have a right to decide what school they attend or what religion they are brought up in.

Parents also have obligations. They are obliged to uphold or, at least, not impede the child's rights under the constitution. For example, parents must ensure (with the assistance of the State) that their children receive an education.

In instances where the family has broken up or parents have died, the courts will decide who has legal custody. The people who have custody, the custodians, then step into the legal role previously occupied by the parents.

All of this changes once the person reaches the age of eighteen. At eighteen a person is legally an independent citizen of the State. They are then responsible for themselves and have the same rights and protections as all other citizens. The critical point here is that parents of an adult child no longer have the legal rights and obligations they had as parents of a minor. Legally, parents have no right to control how their adult son or daughter is treated by others nor have they any control over their son's or daughter's own behaviour. This applies to all adult children, including those with a disability. For example, a parent of an adult child has no legal right to instruct a service provider from whom their adult child is receiving a service in relation to their health care or where or how they live or how or on what they spend or invest their money. Neither can a parent make their adult child attend a doctor or tell them how to live their lives or what to do with their money.

##### **A Grey Area for Rights**

This leaves the parents of adult children with intellectual disabilities and/or autism in a difficult position. They have no rights, yet feel, for very good reasons, that they are still obliged to look after their child. In practice, parents will find that they will still be consulted as parents and primary carers, not least because they will probably still be providing a significant amount, if not the majority, of the care and support for their adult child. In reality they have no legal footing.

Parents can (as too can the State) go to the courts and seek to be appointed the 'legal guardian' of their adult child. This would reinstate the rights and obligations they had as parents when their child was a minor. This may not lead to the solution parents were looking for as the courts can impose

restrictions on a guardianship or could possibly appoint someone else as the guardian or a joint guardian. Indeed, the State could itself go to court and seek to have a person made ‘ward of court’ in which case the State effectively becomes the legal guardian of that person.

In practice, you will, no doubt, find that the family is consulted to varying degrees in the vast majority of all situations. However, nothing is done legally and the families, the State and service providers proceed in what is a legal vacuum. For the most part this works with all parties taking some responsibility to uphold the human rights and provide for the needs and wishes of the person. Standards of care such as the HIQA Standards for residential accommodation (see Part C), the constitution and the UN Convention on the Rights of People with Disabilities all help. However, this legal vacuum can lead to difficulties and the sooner the legal status of all concerned is sorted out the better.

### **Understanding your Obligations**

In all of this it is important for families to understand what their obligations are and, importantly, where their obligations end and those of the State commence. Families have, in the case of adult children, no more nor less legal responsibility to support that adult child in accessing their rights than the State has. What this means is, that the family could, if they wished, walk away and let the State provide for their family member and let the State secure equal rights for them. In reality, no one would wish to wholly ‘abandon’ their family member to the State. Most families would not trust the State and would also, understandably, feel emotionally, morally and ethically bound to support their family member.

Unfortunately, because of this, the State often stands back from its obligations and allows the family to carry more of the responsibility than they should and, in a lot of cases, more than they can bear. Families need to recognise this in their dealings with the organs of the State (for example, the HSE) and feel empowered to force the State to live up to its obligations to its citizens.

As referred to earlier, there are existing pieces of legislation to assist. These are most notable in the area of health and welfare - the Health Acts. Under the Health Acts, the State, through the HSE, has the legal obligation to uphold and provide for the health and welfare of your family member. It is often very worthwhile to remind HSE officials (and service providers) of this when discussing the care and supports your family member needs.

### **Future Developments – legal capacity legislation**

In many countries legislation has been enacted to deal with the the rights and obligations of families in cases where a family member cannot represent themselves. However, in Ireland we have not done so as yet. Legislation known as the ‘Legal Capacity Bill’ is being actively worked on by the Dail and its Committees, however, there is still some way to go before we will see the legislation in place. The aim of this legislation is, amongst other things, to clarify the legal standing of families and other individuals (for example, healthcare professionals) in terms of their rights and obligations when it comes to the care and support of a person who is deemed not capable of ordering their own lives. It is a very complex issue and will require very careful consideration once published.

## **Don't Forget The Person That is Your Child**

It is important for families and, particularly, parents to recognise that the person with intellectual disabilities and/or autism in their life is independently entitled to all of their rights and that just like any other child, must be allowed to (in so far as they can) express themselves as individuals. Just as with any child becoming an adult, this can be very difficult for parents. It is difficult to let go.

As set out in the section on 'person centered planning (see Part B), all those involved in supporting the person with disabilities must have regard for the wishes of that person.

This can be a particular challenge for parents and other family members. Up to the age of eighteen they have, in their eyes, been dealing with a child. Because of the nature of intellectual disabilities and/or autism, however, the usual signals and moves by the child to be recognised and allowed to be an adult are obscured or even absent.

## APPENDIX A

The following is a list of bodies with responsibilities for assisting citizens in accessing their basic human rights:

### **Ombudsman**

18 Lr. Leeson St., Dublin 2. Tel: 01-639 5600,  
LoCall: 1890-223030(from outside 01 area),  
E-mail: ombudsman@ombudsman.gov.ie

### **Ombudsman for Children**

Ombudsman for Children's Office, Millennium  
House, 52-56 Great Strand Street, Dublin 1.  
Tel: 01-8656800 or Free-phone 1800-202040, e-  
mail: oco@oco.ie

### **Equality Authority of Ireland**

Birchgrove House, Roscrea, Co. Tipperary, Ireland.  
Tel: 0505-24126.  
e-mail: info@equality.ie

### **Irish Human Rights Commission**

4th Floor, Jervis House, Jervis Street, Dublin 1.  
Tel: 01-8589601 e-mail: info@ihrc.ie

### **Citizens Information Board**

Ground Floor, George's Quay House, 43 Townsend  
St, Dublin 2, Ireland  
Tel: 01-6059000 e-mail: info@ciboard.ie or  
eolas@ciboard.ie

## APPENDIX B

Some of the titles of the more pertinent 'detailed obligations' on signatories to the UN Convention of the Rights of Persons with Disabilities.

- Equality and non-discrimination
- Women with disabilities
- Children with disabilities
- Awareness – raising
- Accessibility
- Right to life
- Situations of risk and humanitarian emergencies
- Equal recognition before the law
- Access to justice
- Liberty and security of the person
- Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Freedom from exploitation, violence and abuse
- Protecting the integrity of the person
- Living independently and being included in the community
- Personal mobility
- Freedom of expression and opinion, and access to information
- Respect for privacy
- Respect for home and family
- Education
- Health
- Habilitation and rehabilitation
- Work and employment
- Adequate standard of living and social protection
- Participation in cultural life, recreation, leisure and sport