



WISDOM SERVICES

Promoting dignity and justice for
people with an intellectual disability

An introduction to Wisdom Services

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Wisdom Services

Promoting Justice and Dignity for people with Intellectual Disability

Daughters of Wisdom

The Daughters of Wisdom are a worldwide Christian movement which is founded on the values of love, justice and the inherent dignity of the person.

Daughters of Wisdom and Cregg House: A Short History

The Cregg House story began over fifty years ago when the Daughters of Wisdom (then known as the Sisters of La Sagesse) came to Sligo in 1955 at the invitation of the Department of Health to establish a residential centre for people with an intellectual disability¹. At that time in the North West of Ireland, services for individuals with intellectual disability were largely non-existent except for those provided by the local psychiatric hospitals. In the beginning, Cregg House accommodated twenty-four children and a community of eight sisters. From these beginnings the services have gradually and consistently evolved and developed in order to meet emerging needs and to keep abreast with the latest models of care. Today, Wisdom Services, Cregg Sligo, offer high quality services to more than 200 individuals with intellectual disability, their families and advocates.

Appendix 1 provides a brief outline of some of the significant milestones in the history of Wisdom Services since their foundation in 1955 up to the present time.

¹ Intellectual disability can be defined as “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development. It may be described in terms of a mild, moderate or profound intellectual disability. The terms intellectual disability or intellectual disabilities, are the terms that are increasingly recognised throughout the world. The terms commonly used in the U.K are learning disability or learning disabilities and in North America, developmental disability, mental retardation and mental handicap. An intellectual disability should not be confused with a psychiatric disability or mental illness, although a person with and intellectual disability may also have a psychiatric disability.

Daughters of Wisdom and the Health Service Executive Partnership

Services need to respond in ways that are appropriate, timely and responsive to the ever changing needs of individuals with Intellectual Disability throughout their lives, that is from infancy to childhood, to adolescence, to adulthood, to middle age and to old age².

This approach places demands on Wisdom Services :-

- To creatively negotiate and meet the wide-ranging challenges and opportunities posed at the various stages of the individual's life.
- To have the capacity to change and adjust the role it plays in *supporting* an individual throughout the full spectrum of his/her lifespan and that of his/her family³.

Therefore in 2002 the Daughters of Wisdom and the Health Service Executive (HSE) formed a partnership approach to examine their current services and to look at how future Wisdom Services developments would enshrine their founding principles and reflect best practice.

A report was produced, the main findings of which were:-

1. That Wisdom Services offered a service to over 200 people with intellectual disability, of which approximately 140 currently lived on the Cregg House campus with approximately 60 living in community based accommodation in the Sligo urban area.
2. That, in the main, the people availing of the services are a very vulnerable population including:-
 - An aging population with the associated needs of the elderly
 - People with a severe to profound intellectual disability
 - People with significant challenging behaviour patterns and autism⁴
 - Children with intellectual disability and complex health needs⁵

² There are approximately 26,000 people in the Republic of Ireland registered as having an intellectual disability on the National Intellectual Disability Database (NIDD). The database also shows that people with an intellectual disability, particularly in the moderate, severe and profound levels of intellectual disability are living longer. For example those aged 35yrs and over are recorded as 29% of the total in 1974 and increased to 48% of the total in 2007. This changing profile suggests that more residential services and other services designed specifically for older people with intellectual disabilities will be required.

³ Supports are services and approaches necessary to promote the development, education, interests and personal well being of a person with intellectual disabilities

⁴ Some children and adults with severe intellectual disabilities typically display behaviour which may put them or others at risk or which may prevent the use of ordinary community facilities or a normal home life. This behaviour may be in the form of aggression, self injury or disruptive and destructive behaviours. These behaviours are not under the control of the individual concerned and are largely due to the individual's lack of the ability to communicate.

⁵ The term "complex disabilities" refers to the presence of a combination or range of issues such as physical, medical or neurological problems that people with intellectual disabilities may have.

- 3: That Wisdom Services have developed expertise in providing specialist services at Cregg House and recommended that Wisdom Services continue to provide and develop the range of specialist services in the future in partnership with the HSE
- 4: That the current living accommodation on the Cregg House campus is not adequate to meet the changing needs of service users. It did not meet Health and Safety standards, was overpopulated and not reflective of future service provision⁶.
- 5: It found that the service model - *a congregated living environment*⁷ did not reflect the principles of justice or acceptable best practice models
- 6: The report also found that most of the houses currently in use in the community did not meet the changing physical needs of service users, in that most are two storey houses and not suited to users who may not have full mobility.

The report therefore recommended that Wisdom Services will continue to provide a range of service supports in the Sligo / Leitrim catchment area to its present and future service users and families. These services may over time become more localised and embedded in existing communities in this region. As more specialist services are developed by Wisdom Services the need may occur for such services to be provided outside of the catchment area in neighbouring counties, for example Donegal.

⁶ Today many of the services provided to people with an intellectual disability are rooted in the “rights based” thinking- that people with intellectual disability have a right to live full and active lives and be active participating members of their own community, as set out in the O’Brian Principles (1987) of: Inclusion, Choice, Dignity, Respect, Participation and Contribution.

⁷ In the past people with intellectual disabilities were often taken from their family and community and sent to large residential institutions. These large institutions are referred to as “*congregated settings*” in that they put a large number of people with intellectual disabilities together in the one place but away from “society”. Therefore there was a time both internationally and in Ireland that services were developed apart from communities or what could be termed “normal society”.

Wisdom Services providing Specialist Services

For many people with intellectual disabilities, the presence of ill-health may impair their ability to achieve the best possible quality of life. The attainment of a good standard of health (at least as good as the rest of the population) is a reasonable goal. When people with intellectual disabilities move from residential care to a place in the community, the new HSE primary care teams can play a key role in providing them with good-quality healthcare. Primary care is based on an ability to assess, investigate and manage a range of common and complex conditions, which requires an awareness of the specific needs of the local population served.

Health needs of people with intellectual disabilities

People with intellectual disabilities have the same range of conditions as the general population, and thus, on one level, have the same primary care needs as the general population. These include:

- *the treatment of acute and chronic illness*
- *appropriate referral to hospital or other healthcare setting*
- *Health education.*

People with intellectual disabilities also have specific additional needs, for example:

- *identification and treatment of conditions is more complex owing, in part, to associated difficulties with communication*
- *Some conditions are seen with greater frequency in this population*
- *Conditions are seen which appear to be more common in specific syndromes associated with intellectual disability*
- *Evidence suggests that early mortality is increased in this population compared with the general population (Morgan et al., 2001)*

People with intellectual disabilities suffer from common conditions: although the range of conditions is the same as in the general population, identification and treatment are more complex. This is due, in part, to associated difficulties with communication, which leads to under-recognition of common disorders.

Certain conditions are more common in people with intellectual disabilities: figures vary for the prevalence of the common associated conditions in people with intellectual disabilities, such as epilepsy, behaviour problems, psychiatric illness and mobility deficits. These conditions are not unique to people with intellectual disabilities but their higher prevalence means that they are an important part of any assessment in this disability group.

Certain syndromes that cause intellectual disability are particularly associated with an increased risk of specific conditions, including the following example:

- *Down's syndrome is associated with increased risks of cardiovascular disease, respiratory disease, eye disorders, Alzheimer's disease, leukaemia and hypothyroidism*

Increasingly, knowledge of these specific patterns of illness will guide the management of healthcare for these groups.

Intellectual disability is associated with early mortality: while life expectancy overall is improving, people with intellectual disabilities continue to have a reduced life expectancy compared with the population as a whole.

Barriers to healthcare.

People with intellectual disabilities may receive inferior primary care services than the community generally. This is likely to be caused by a number of barriers, including:

- *Physical difficulties, behaviour problems and communication difficulties*
- *Medical staff related issues, which include a lack of specialist knowledge about the health issues likely to be experienced by people with intellectual disabilities. Also the recognition of the need for additional service time and resources by many people with intellectual disabilities.*

Wisdom Services: Providing Specialist Services in the North West

Wisdom services have developed, over many years, a range of specialist services best suited to the needs of persons with intellectual disabilities. We plan to continue to provide a full range of specialist services to all who would benefit from them. We will do this in partnership with the Health Service Executive. The range of specialist services includes:

The Older Person /Dementia and End of Life Care Services

Wisdom Services will continue to develop a range of services addressing the specific needs of older people with intellectual disabilities which will include;

- Supporting people in their own homes and communities
- Providing person centred day and recreational services
- Providing a mobile memory clinic
- Providing a range of respite and fulltime residential placements
- Providing a specialist and purpose built residential dementia and end of life care unit
- The services of experienced and skilled specialist staff

Significant Challenging Behaviour and Autism

Wisdom Services will continue to provide and develop the following services;

- Specific person centred programs which incorporate both residential and day service provision.
- Specialist occupational programs
- A range of respite and residential placements
- Purpose built accommodation
- Support for families and individuals in their homes and communities
- The services of experienced and skilled specialist staff

Children with Complex Needs

Wisdom Services will continue to provide and develop the following services;

- Support for families and individuals in their own homes and communities
- Purpose built respite and residential accommodation
- A range of high quality person centred support programs
- The services of experienced and skilled specialist staff

Services to people with severe and profound intellectual disabilities

Wisdom services will continue to provide and develop the following services;

- A range of purpose built residential accommodation
- A range of person centred day and recreational services
- The services of experienced and skilled specialist staff

The Challenge

The vision of Wisdom Services is to provide a model of service which reflects the founding principles of love and justice and which promotes inclusion and integration into local communities while also providing specialised services. Our approach develops a set of values in terms of a future development in that:-

1. It is about **transforming the lives** of service users as against simply transferring people from one place to another.
2. It is about **building homes** not just houses. A home is where one belongs, is safe and secure and is part of a community.
3. As a service, our main role in the future is in **supporting communities** so as to enable the person with intellectual disability to participate in the life of that community and ensure that mainstream services are available to meet the needs of a diverse population.

To achieve this, the future plan has three interrelated and interdependent goals.

Goal 1

This goal centres on the redevelopment of the present site of the Cregg House campus and adjoining lands to form a new integrated community. (See The Cregg Project)

Goal 2

This goal focuses on the relocation of service users currently living on the campus of Cregg House to community settings (80 people approx plus day service provision).

Goal 3

This strand focuses on service users currently living in the community and acknowledges their changing needs in terms of both appropriate housing and support structures

Running parallel to these goals will be the continuation and development of services at local community level in Sligo and Leitrim. Specialist services may be extended by arrangement with the HSE to Donegal at some future date.

Goal 1: The Cregg Project

The National Spatial Strategy provides the context for local and regional planning with an overriding objective for all Local Authorities of promoting strong urban centres, delivering effective infrastructure networks, and providing key social, cultural and recreational infrastructure. In that context **Wisdom Services** propose to build a new sustainable community at the current site of Cregg House, which is in a high value natural environment with views of mountain and sea.

At the core of the development is the acknowledgement of the complex and specialist needs of people with disabilities who will be an essential part of this new community from the beginning. This new community at Cregg will have its focus on the inclusion and participation of people with disabilities in the community, using the social model of disability and encouraging active citizenship.

The homes of people with disabilities and the homes of other residents in this unique development will be integrated. The concept is to develop a natural harmony within the community in which support structures can be best utilised, taking account of the need to ensure value for money.

In most circumstances, development plans are based on general norms and do not take into account the complexity of the supports that are required for some people with intellectual disabilities. However, **the Cregg Project** is a radical departure from this, in that it recognizes the varied and complex needs of people with intellectual disabilities. It endeavours to construct a development plan that at the initial stages acknowledges and incorporates the required supports. In fact the plan is literally built up around the core concepts of addressing the full spectrum of needs of all those who will live in this new community. There will be strong emphasis on the **universal design**⁸ approach throughout. The benefit of this approach will be that all of the accommodation will be suitable for use by people with disabilities, people with mobility limitations of a temporary or permanent nature as well as others who do not have disabilities.

What emerges, therefore, is a new concept in design, a concept which is not just represented by buildings and the physical environment but characterised by **sustainable communities**⁹, structured to spontaneously facilitate maximum participation and integration of some of the most vulnerable people in our society. This unique approach to integrated, universal design will, it is hoped, lead to the adoption of new norms in the design of buildings of new communities.

⁸ Universal Design refers to 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 and disability.

⁹ A sustainable community is seen as the residential and workplace surroundings in which people live and thrive, where there is a balance and integration of the social, economic and environmental components that define a community area. In short these communities are likely to be: safe and inclusive, well planned, built and run, offering equality and opportunity for all.

Goal 2: Relocation of Service users to Communities

In the same context our Sligo / Leitrim community placement project is in partnership with the HSE, Local Authorities and the Sophia Housing Association whereby people with intellectual disabilities are facilitated to live independently in living accommodation suited to their needs in ordinary communities. We currently have projects in Sligo town, Drumcliffe, and Tubbercurry.

Goal 3: Supporting Service Users currently living in the community

Many of our older houses in the community do not meet the changing needs of service users particularly in relation to physical mobility. We, therefore, need to develop a range of housing options such as single story houses, adapted existing houses and fully accessible apartments suitable for people with mobility limitations. We are currently developing some projects in the Sligo urban area

Appendix 1

Significant Milestones in the History of Wisdom Services

1965 The first phase of building at Cregg House was commenced to increase residential accommodation for children. In the same year The Department of Education officially recognised and sanctioned a four teacher school.

1966 Official recognition was granted by An Bord Altranais (Irish Nursing Board) for the establishment of a School of Nursing in intellectual disability at Cregg House

1973 The second phase of building at Cregg House was completed providing for children and adults. This consisted of bungalow style accommodation on the site in a village type complex which was the service model at that time

A new chapel and convent were also completed.

1974 St. Cecilia's National Special School was officially opened on the Cregg House campus.

1978 A multidisciplinary approach which included Departments of Psychology, Speech and Language Therapy and Social Work was initiated.

1981 The first community house in Sligo town opened. In the intervening years several houses were opened bringing the total number of houses occupied to date to thirteen.

1984 Two purpose built units were established for people with behaviours that challenge. This followed agreement with the North Western Health Board(N.W.H.B) that Cregg House should become the Regional Unit for people with behaviours that challenge.

1986 In partnership with the Department of Education, St. Cecilia's Special School commenced an educational programme for persons with a severe or profound degree of intellectual disability.

1989 Official approval was granted by An Bord Altranais for Post Graduate Course in Behaviour Modification Therapy. This became first such course to be offered by a Nurse Training School in Ireland in the field of Intellectual Disability.

1994 Respite Care Service in collaboration with NWHB commenced.

1998 Diploma in Nursing programme commenced which formed initial links with St Angela's College Sligo.

2001 Day Services expanded into the community with the opening of Nu Haven Enterprises located at 51 John Street Sligo.

2002 The Daughters of Wisdom appointed an interim Board of Directors to maintain their status

as a Voluntary Agency and to preserve the Christian ethos of the Service.

2004 The Centre of Nursing & Midwifery Education, HSE, was established on the ground floor of Cregg House, formerly the School of Nursing.

2005: Golden Jubilee celebrations. A Service review was undertaken by the Daughters of Wisdom

2006: Process of transformation of the service began.

Advocacy Group established.

2007 A new action plan was officially launched by Sr. Jean Quinn, Provincial of the Daughters of Wisdom, the intention of which is to significantly improve service provision over the coming years.

A Children's unit was officially opened.

Appendix 2

Selected Policies and Legislation Relating to Persons with Disabilities

Office for Disability and Mental Health

An Office for Disability and Mental Health was established in January 2008 to support the Minister of State for Equality on Disability Issues and Mental Health at the Department of Health and Children. This office, while located in the Department of Health and Children has responsibilities and authority in a number of other departments that deal with aspects of disability and mental health.

National Disability Strategy

The Government launched the National Disability Strategy on 21 September, 2004 with the intention of underpinning the participation of people with disabilities in Irish society. The strategy builds on existing policy and legislation, including the policy of mainstreaming public services for people with disabilities. It has been endorsed in the social partnership agreement - Towards 2016.

The key elements of the strategy are:

- The Disability Act 2005
- Sectoral plans prepared by six Government departments
- The Citizens Information Act 2007, which equips the Citizens Information Board (formerly Comhairle) to provide a personal advocacy service for people with disabilities

- The [Education for Persons with Special Educational Needs Act 2004](#)
- A multi-annual investment programme worth €900 million targeted at high-priority disability support services to run until 2009

Disability Act 2005

The Disability Act 2005 is a positive-action measure designed to support the provision of disability-specific services and improve access to mainstream public services for people with disabilities. All sections of the Disability Act 2005 have now been commenced.

- Part 1 of the Act commenced on 1 June, 2007 - for children up to age five and provides a statutory entitlement to assessment of needs, service statements and redress.
- Part 2. Arrangements for the implementation of Part 2 of the Act for older children and adults are set out in the [sectoral plan](#) of the Department of Health and Children. A review of the Act will take place before the end of 2010.

International Policy on Intellectual Disability

Council of Europe Disability Action Plan 2006–2015

The [Council of Europe Disability Action Plan 2006–2015](#) aims to serve as a practical tool to guide member states in developing strategies to bring about full participation of people with disabilities in society and ultimately mainstreaming disability throughout all policy areas and programmes.

The plan was adopted in April 2006 and launched at the European conference “Improving the Quality of Life of People with Disabilities in Europe”. The core of the plan consists of fifteen action lines that set out key objectives and specific actions to be implemented by member states.

Promotion and implementation of the plan is currently under review, and the outcome of the review is expected in the first half of 2009.

UN Convention on the Rights of Persons with Disabilities

On 30 March, 2008 Ireland signed the [UN Convention on the Rights of Persons with Disabilities](#). The convention is a major human rights treaty, joining other human rights treaties such as the Convention on the Elimination of all Forms of Discrimination against Women and the Convention on the Rights of the Child. It represents an important advance for people with disabilities throughout the world.

The Government has approved the establishment of an interdepartmental group to advise on the changes that may be needed to the National Disability Strategy to enable Ireland to ratify the

convention. The group met for the fourth time on 2 December, 2008 and is consulting with representatives of people with disabilities during the course of its work.

Appendix 3

SUPPORTS AND INTELLECTUAL DISABILITIES

Supports are services and approaches necessary to promote the development, education, interests, and personal well being of a person with intellectual disability. Supports can be provided by a parent, friend, teacher, psychologist, doctor, or by another person or organisation appointed to provide the service required.

The concept of supports originated about 15 years ago and has revolutionized the way services are provided to persons with intellectual disability. Rather than limiting an individual into choosing from a range of services that are available, the needs of the individual are assessed and then services tailored to best meet those needs. The supports approach also recognizes that individual needs and circumstances will change over time.

Why are supports important?

Providing supports designed to meet the needs of each individual can improve personal functioning, promote self confidence and independence, and enhance the well being of a person with intellectual disability. Supports also lead to communities understanding better the abilities of persons with intellectual disabilities and encourage doing all they can so that that people with disabilities play their full part in community life. Focusing on supports as the way to improve education, employment, recreation, and living environments is an important part of a person-centred approach to providing care to people with intellectual disability.

What are some examples of support areas and support activities?

Home Living Activities

- Using the toilet
- Laundering and taking care of clothes
- Preparing, cooking and eating food
- Housekeeping and cleaning
- Dressing
- Bathing and taking care of personal hygiene and grooming needs
- Operating home appliances and technology
- Participating in leisure activities within the home

Community Living Activities

- Using transportation
- Participating in recreation and leisure activities
- Going to visit friends and family
- Shopping.
- Interacting with community members
- Using public buildings and settings

Social Activities

- Socializing within the family
- Participating in recreation and leisure activities
- Developing personal relationships
- Making appropriate sexual decisions
- Socializing outside the family
- Making and keeping friends
- Communicating with others about personal needs
- Engaging in loving and intimate relationships
- Offering assistance and assisting others

Changing Values & Services

In the past people with intellectual disabilities were often taken from their family and community and sent to large residential institutions. These large institutions are referred to as "*congregated settings*" in that they put, a large number of people with intellectual disabilities, together in the one place but away from "society". Therefore there was a time both in Ireland and internationally when services were developed apart from communities or what could be termed "normal society".

The prevailing message at the time was that it was better for the individuals, their families and society if they were taken away and cared for. This amounted to a form of "out of sight out of mind" approach. As a result many people with intellectual disability were forced to live on the margins of society away from family and friends. There are many people with intellectual disability who have now found their voices and have described their lost opportunities, their loneliness and their "lost lives", apart from their family and communities.

Today many of the services provided to people with an intellectual disability, are rooted in the "rights based" thinking - that people with intellectual disability have the right to live full and active lives, and be active participating members of their own community, as set out in the O'Brien Principles (1987) of:-

- Inclusion
- Choice
- Dignity
- Respect
- Participation and Contribution

"Nothing about Us without Us"

People with intellectual disabilities are now speaking up for themselves. The development of "self-advocacy" groups in the 1980s, led to the recognition that people with intellectual disabilities have a voice that must be listened to. The slogan of this advocacy movement is *"Nothing about Us Without Us"*.

While, broadly speaking, service responses are moving towards a social model, which envisages more inclusive roles for people with intellectual disabilities in our communities, while also ensuring that a holistic or whole person approach is central to the type and range of service supports provided.