

**Vision Statement for Intellectual Disability
in Ireland for the 21st Century**

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

Discussion Document

**prepared by the National Federation of Voluntary Bodies
Providing Services to People with Intellectual Disability**

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Contents

	Page
The Policy Context	3
Overall Vision	3
Principles	
1. Self-determination - being supported to live a life on one's own terms	4
2. Friendships, Relationships - meaningful and freely chosen	4
3. Inclusion	5
4. Equity	6
5. Equal citizenship	7
Issues to be addressed in the vision statement	
1. Designing Responsive Supports	8
2. Person and Family Centered Approaches in the Life Cycle	9
3. Risk Management	10
4. Service delivery	11
a. Mainstreaming	
b. Professionalism/Specialisation	
c. Models of Services	
d. Partnership	
e. Best Practice and Innovation	
f. Sub-populations	
Design Attributes of a Policy Document and of a Policy Development Process	14
References	16
Appendix 1: Reference Documents: Constitution of Ireland - Bunreacht na hEireann, Proclamation of Independence, UN Declaration of Human Rights, UN Convention on the Rights of Persons with Disabilities	
Appendix 2: Quality and Fairness: A Health System for You - Health Strategy, Linking the Factors that Determine Health	
Appendix 3: Towards 2016: Ten-Year Framework Social Partnership Agreement 2006 – 2015, Part III, The Lifecycle Framework, Section 33	

The Policy Context

The National Federation of Voluntary Bodies believes that Government should develop a vision for intellectual disability at this time.

Why is there a need for a Vision Statement for Intellectual Disability at this time?

- The last vision statement or policy document for intellectual disability was *Needs and Abilities 1990*.
- The language and concepts in it are not relevant for service provision or for people's lives in the 21st century.
- There is a need for a vision statement that takes account of new and existing legislation e.g., Disability Act 2005, Education for Persons with Special Educational Needs (EPSEN) Act 2004 and forthcoming Mental Capacity legislation.
- The new Vision Statement needs also to take account of the Government's National Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities.
- People with intellectual disabilities have limited access to the determinants of health as set out in *Quality and Fairness (2001)*. . . . *The definition of health used in this Strategy places a value on quality of life; the emphasis will not be on medical status alone. The health system in Ireland encompasses both health and personal social services and these must be accessible and well co-ordinated. This means reaching out to groups and individuals to ensure they can understand their entitlements and access the services they need. It also means recognising the formal and informal roles of family and community in improving and sustaining social well-being in society.* We believe that this definition is vital for people with intellectual disability to be supported to live a life on their own terms (Appendix 2).
- There is also a need for a vision statement which gives credibility and traction to existing Government policy including *Towards 2016 and Quality and Fairness* which has explicitly stated the interests of people with disabilities (Appendix 3).

OVERALL VISION: *Being supported to live a life on one's own terms*

Above all people have a deep rooted desire to belong, to be in relationship, to live within the intimacy and security of their family and friends, to be included in the greater life around them with all its attendant possibilities for hope and fulfillment and to do so, to the greatest extent possible, on their own terms. The implications of this simple truth will determine our actions on behalf of all citizens with Intellectual Disabilities.

Principles

1. Self-determination, being supported to live a life on one's own terms:

Being supported to live a life on one's terms is, we suggest, a very appropriate policy vision. To live a life on one's own terms, it is important that a person has been exposed to, and experienced, the choices available. The expression of citizenship and self-determination presupposes the power to choose. A number of related implications flow from this:

Challenges:

- There is compelling evidence that what many people with an intellectual disability want in their lives is not addressed in current service models and support arrangements. (e.g., The Quality of Life of People with Disabilities in Ireland in 2007; Outcomes for People Project; National Intellectual Disability Database; National Federation People Connecting, 2007; National Federation Research Strategy, 2008). This is a major challenge to the entire system of provision which needs to be addressed.
- The decision making structure within prevailing service provision results in independent advocacy being defined as the solution. When there is real power sharing in the design of support arrangements a natural process of advocacy can be designed into the process.
- A framework for promoting and safeguarding supported decision-making needs to be developed. (This will have direct implications for the forthcoming Mental Capacity Bill).
- Individualised funding is strongly emerging as an effective – and for many, a necessary – modality for empowering choice. (What will be the implications for service providers in the context of current and future employment contracts and on the availability of therapists, care workers etc trained to the required standard).

2. Friendships, Relationships - Meaningful and Freely Chosen:

More than any other aspect, the range and character of one's relationships is likely to determine the extent to which one experiences a life of fulfillment and quality. The world of relationship is characterised by the dimension of interdependency. Persons with an intellectual disability have an elevated exposure to their interdependency. This national policy document should recognise the primacy of family and other natural support networks e.g., relationships with families, friends, neighbours and people living in the community.

Supporting, strengthening and safeguarding family and other natural networks of support must lie at the heart of the policy and all of the actions flowing there from. The policy should support the development of meaningful, freely chosen relationships which incorporate the broad range of relationships experienced by every other citizen from friendships through to intimate relationships.

Challenges:

- More than any other issue the importance of relationships in the lives of people with disabilities will challenge the way supports and services are organized. Many people in the disability service system live lonely lives. They may lead busy, even well resourced lives. Yet somehow the pervasive sense of “bowling alone together” remains palpable.
- While loneliness is an increasing feature of contemporary society there is something about the nature of the present support system that accentuates, albeit unintentionally, the likelihood that people with disabilities only know those who are paid to know them.
- The professionalisation of services has a paradox that must be addressed. People need appropriate supports and at times this may require a high degree of specialist expertise. Yet the deepest human needs may remain unacknowledged let alone addressed within the contemporary system. The system seems to have acquired almost prophylactic properties which insulates communities and isolates people with disabilities. Our present system is built around models that risk promoting the serial solitude of lifelong group living. It also struggles to address the isolation of those who live alone in “independent living”. The obvious question arises then is whether we are focused on things that really matter most to people with disabilities and their families.
- The things that are focused on in developing professionals, both clinical and direct support staff, the conception of what it is paid supports should address, the methodologies employed, the nature of engagement with people and families show a disconnect from the priorities of those who have to rely on the system.

3. Inclusion:

Inclusion is the foundation for developing a sense of belonging. It offers the opportunity for participation in the world about us. It provides the context for developing a personal and social identity, for building relationships, reciprocity and contribution. Being included means

being taken seriously as a person. It assumes normative expectations. In short being included is the gateway for getting a life.

Challenges:

- Inclusion should not be confused or equated with *location*. Many contemporary services are located in community settings but only weakly support effective inclusion. The realisation of inclusion involves a high level of participation, engagement and the building of roles and relationships.
- Neither should the concept of inclusion be confused or equated with that of *integration*. Inclusion is not about mere physical presence but rather concerns itself with connectedness and a quality of relationship. The *Equal Lives* document published in Northern Ireland in 2005 sets out the core aspects of inclusion very clearly: **People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community.**
- Inclusion recognises both peoples' need for individual support and the necessity to remove barriers to inclusion that creates disadvantage and discrimination. Inclusion is only possible on the basis of equality of opportunities to access and to participate in education, employment, leisure and other aspects of community life.
- Inclusion is more likely to be achieved if peoples' connections are maintained at a local level through involvement in local schools, housing, employment, leisure etc.
- Inclusion must also be recognized as a reciprocal relationship and this policy should recognize the need to include communities in the life of the person with an intellectual disability.

4. Equity:

Adults with disabilities and families of children should have the right and opportunity to direct their own supports and have access to the resources to do this. This should happen regardless of the nature and degree of disability and where they live in the state. The process of defining need is extremely powerful in determining the nature of support solutions. The approach to defining need must reflect both Person and Family Centered practice.

Challenges:

- From the moment families with young children come into contact with the disability system they are likely to be socialized into a menu of professionally designed solutions which begins a long slow process of inadvertent disempowerment. Typically there is an absence of focus on family goals and the development of the families' capacities. Assessment remains focused on child development goals which are determined by expert assessment processes. While this is a legitimate and important element of support it is based on a limited and limiting perspective. The power of natural supports is poorly harnessed and a message of dependency on the power of the professional decision maker is delivered.
- Frequently families will demand more and more specialisms as this has been sold to them as the solution. They become engaged in campaigns of advocacy to increase the number of professionals in their lives or the number of sessions they receive etc. Solutions are identified before problems are truly defined.
- Families, even those that are very engaged in their communities, often struggle with a sense of isolation around the child with an intellectual disability. Keeping families and children connected to the natural supports in their communities is critical. Creating confident families who are equal partners in decision making requires a family centered approach.
- The issue of needs assessment and resource allocation is highly fraught. The approach to needs identification and in particular the quality of problem solving that follows is a critical aspect that requires much more attention than it currently receives. It determines not only the quantity of resource allocation but also is fundamental to the effectiveness of supports and the challenge of sustainability.

5. Equal Citizenship:

The person with an intellectual disability has the same rights, responsibilities and opportunities as every other Irish citizen. The person with an intellectual disability should have the opportunity to be an equal and active citizen. As set out in the Taskforce on Active Citizenship (2007), active citizenship concerns everyone. This taskforce set out 10 guiding principles on how to achieve active citizenship which involves education, life-long learning, engagement in the democratic process particularly at a local level and requires leadership

(Report of the Taskforce on Active Citizenship, 2007). These principles are equally true for people with an intellectual disability.

Challenges:

- The implications of anchoring the policy in the concept of citizen as opposed to anchoring it within the concept of consumer or client should be clearly articulated. (The difference between a posture which strives to *be of service to citizens* as opposed to one which seeks to *service citizens* should be very apparent.)
- The policy should set out the relationship between the interplay and balance of rights and responsibilities in the context of the citizen with an intellectual disability.
- The document should describe the enrichment of society that flows from succeeding in supporting persons with an intellectual disability give effective and active expression to their citizen role. Ideally, this should be complemented by a description of how failure to support citizens with disability to realise their citizenship impoverishes both the person with an intellectual disability and society as a whole. (A vision of society, in addition to a vision of a good life for a citizen with intellectual disability, should inform and animate the policy document).

Issues to be Addressed in the Vision Statement

1. Designing Responsive Supports:

The principles of equal rights, inclusion, relationships and self determination require a unifying value that gives shape to their implementation. Person and family centered values represent the organizing principles which provide a coherent design for support arrangements.

While person centered practices are often espoused in policy documents, the foundation for this, which is family centered practice, is omitted. It is as though there is an abrupt shift in the support paradigm on a persons 18th birthday. Whether this reflects the nature of different professional perspectives in Children's and Adult Services is worth consideration.

The intention which underlies both person and family centered approaches is that those at the centre of support arrangements do so in partnership with paid supports. Supports and

services are organized to reflect the person or families' priorities as they define them. Person and family centered support arrangements extend to looking at what is available in the mainstream and wider community rather than limiting services to what is typically available within separate disability systems. Furthermore, people and family centered services promote social inclusion and seek to avoid fostering inappropriate disempowering dependencies.

2. Person and Family Centered Approaches in the Life Cycle

Families are the primary nurturers, supporters and advocates throughout the life cycle of the citizen with a disability. In the early years and through primary school, priorities are determined from the families' perspective. As the child enters adolescence and young adulthood, a subtle and intentional transition begins to occur. The maturing young person becomes increasingly involved in decision making. This subtle process of transition continues into adulthood and the decision making dynamics change. Over time, the perspective of the emerging adult takes increasing primacy of place.

Families by their nature are interdependent entities with lifelong and unique relationships. Families offer connectedness to an extended network of relatives, friends and neighbours. Within the lifecycle of families, the passage of time tends to be marked by typical events such as the departure of children to college or work, new relationships arising through marriage and the arrival of grandchildren etc., the family system changes and as parents' age interdependencies may become increasingly complex. The family member with an intellectual disability may assume particular responsibilities and contributions that need to be properly valued.

When support arrangements are intentional about person and family centered practices, they will adapt in response to the changing requirements of the person and their immediate and extended family, friends, neighbours and other natural supports.

Challenges:

- Issues of independence, interdependency and dependence have to be addressed within the unfolding lifecycle and the unique circumstances of each family.
- Both person and family centered approaches will require person and family centered solutions. This challenges contemporary group support arrangements or multi-disciplinary models.

- The modalities of power sharing with people and families will challenge not just the organisations and professionals involved but also the funders.
- Contemporary approaches to assessment of need will require re-design. The first point of contact between the family and the “system” must be with somebody who does not automatically construe ‘need’ in the context of a traditional menu of professional inputs or out-of-home placements.
- How will policy and the service delivery system ensure:
 - a) That family and other natural support systems are not inadvertently displaced;
 - b) That natural support systems are mobilised and reinforced?
- The policy should address the unfolding interdependencies within families as parents and the person with an intellectual disability age – e.g., the role of the adult person with an intellectual disability as carer.
- The policy should address the issues of how to support carers (income and other supports)? The need to profile the particular needs of families and to involve them as a distinct stakeholder perspective is key to the vision.
- The policy should recognise that people with disabilities can be parents too and should address how to support persons with an intellectual disability in their role as parent.

3. Risk Management

One of the features within the prevailing system of provision is about “ownership” of people. Organisations and professionals take on a role of decision maker which is almost exclusive. When it comes to concerns about safety they struggle with the issue of liability. Sometimes it is the case that families will be more risk averse than the service provider and the provider may take on an advocacy role on the person’s behalf. However there is a great deal of mythologizing about families being risk averse while ignoring the reality that services restrict people in the name of safety quite freely. When people and families are engaged in ownership of their own vision the issue of risk management changes significantly. Partnership with people and families is a foundation for trust and significantly reduces anxieties that arise in the area of risk.

- The policy should differentiate between service provider “volunteers” and members of natural networks of support.
- There is a need to scope and define the concepts of **duty of care** and extended duty of care as they apply to the funder and service provider. How can a policy such as the one proposed integrate paid direct support and “natural networks of support” or “freely given” support.
- Developing a methodology of proportionate risk management for people with intellectual disability is paramount in this policy. People with an intellectual disability should be supported to take risks and be exposed to a normal life in doing so.
- There is a risk of health and safety being interpreted and applied as a brake on inclusion and citizenship. The proper scope of regulation in safeguarding the commitment to citizenship and inclusion needs to be addressed – particularly, the unintended restrictions and barriers which a narrow interpretation of regulation may introduce. The entire panoply of safety legislation and structures to enforce this is not balanced by an equivalent support for people’s rights. When organisations begin to be liable for rights restrictions then the equation will shift.

4. Service Delivery:

The policy document needs to explore the limits of the current models of service provision and funding that exist. Some issues for services and models of service delivery need to address the following:

- a) mainstreaming
- b) professionalism/specialisation
- c) models of service
- d) partnership
- e) best practice and innovation
- f) particular subpopulations

(a) Mainstreaming

- The assumption that mainstreaming is merely according people with disabilities access to the same services as the general population is a misleading representation. A positive commitment to the policy of mainstreaming recognises that the manner in which services are currently provided to the general population may not suffice for persons with an

intellectual disability and that a range of active supports will be necessary. Furthermore these supports should be delivered as far as is possible from the same source and in the same location as for other citizens. Persons with an intellectual disability must be “designed into” the service development process from the outset.

- The policy document needs to clearly articulate the core features of what a commitment to mainstreaming entails. It should have particular regard to the National Disability Strategy and the Departmental planning process.
- What needs to be available within the mainstream for the commitment to mainstreaming to be workable?
- How will mainstreaming help employment, education, income support, housing services, et cetera be capacity-enhanced to respond to the needs of citizens with an intellectual disability?
- The document needs to consider if there is a conflict between mainstreaming and the principle of everybody being afforded an opportunity to be fully part of their own community. Mainstreaming is often understood as people with disabilities having to “fit in” to society rather than society being able to accommodate everyone’s needs.
- Disability needs to be designed into mainstream services (in the same way that physical access issues are designed into buildings i.e., at the planning stages)
- Disability needs to be designed into training of professions who will be working with people with an intellectual disability e.g. GPs, Dentists, etc.

(b) Professionalism/Specialisation

- The policy document should address what is the proper role and place of the multidisciplinary perspective within a family-centred and person-centred anchoring of assessment of need?
- How do we accommodate but appropriately situate the specialist input and perspective of multidisciplinary practitioners?

- What are the tensions between the “professionalism agenda” and the promoting equal citizenship value base?
- What is the relationship and correlation between “service quality” and professionalism? (Framing the concept of quality within a citizenship and inclusion paradigm has very direct implications for how one measures quality. Stand-alone service-orientated measures e.g., quality standards for residential centres whilst important are likely to be very weak and indirect indicators of citizenship, inclusion, richness of natural networks of support in one’s life.)

(c) Models of Services

- Best practice models of service which support a quality life for people at average cost or below should be rewarded for providing such a service.
- The policy should address the issues of shared services models and make recommendations for best practice.

(d) Partnership

- The policy should address the issues of partnership
- How can partnership be advanced and promoted in new models of service delivery
- The definition of partnership is a broad one and includes working with people with an intellectual disability, families, government and non-governmental bodies, working with communities, sharing resources, drawing on natural supports

(e) Best practice and innovation

- The implementation aspect of the policy document should identify a national approach to profiling and supporting – and disseminating – best practice and innovation, something along the lines of the English National Development Team. Alternative support arrangements and service model configurations are the key to developing alternative cost structures.

(f) Sub-populations

- The policy document needs to offer comment and guidance on a number of discrete sub populations – persons with autism; those with severe/profound levels of intellectual disability

requiring intensive supports; persons with challenging behaviour and/or complex lifestyles; those with both an intellectual disability and a mental health disability; persons with dementia and Alzheimer's presentation; the older and mentally alert person with an intellectual disability; those persons who psychometrically qualify as having a mild intellectual disability but whose support needs are not such as to render them eligible for inclusion on the intellectual disability database. The document also needs to recognize that challenging behaviour may have a variety of causes– while we use this term, challenging behaviour may result from people not having rights, choice, friendships, relationships, etc. in their lives? – The person's whole life rather than their behavioural symptoms needs to be taken into consideration.

Design Attributes of a Policy Document and of a Policy Development Process

1. The policy should be developed on the basis of **a full engagement** with the various stakeholder groups: citizens with an intellectual disability, family/carers, the various government departments who have developed sectoral plans (Transport, Social & Family Affairs, Environment, Health, Enterprise & Trade; Justice, Equality & Law Reform) Health Service Executive, National Disability Authority, Citizen Information Board, Service Providers, Social Partners, Community representatives, active citizenship groups.
2. The policy document should align with and enhance other work underway in the context of advancing the Disability Act, relevant statutes, operational plans (e.g. HSE's Transformation Programme).
3. It should be accompanied by an implementation plan and by a robust monitoring plan and review process.
4. It should address the requirements and obligations on Ireland in the context of the UN Convention on the Rights of Persons with Disabilities.
5. It should strongly promote the values of equity, person-centredness, and accountability.
6. The policy should inform and shape the development of a range of action channels to give effective expression to the aspirations and commitments set out in seminal documents such

as the constitution, the Disability Act – and in the related National Disability Strategy, in the National Economic Council's Developmental Welfare State, *Towards 2016*, etc.

7. The policy formulation and related implementation programme should provide guidance and direction at national, regional, and local level.
8. The policy document should retain currency and remain serviceable in the event that some other government department assumes responsibility for hosting the overarching responsibility for intellectual disability. (This policy document will be generational in its time-frame.)
9. It will inform the development of a strategy for dealing with such core contemporary challenges as
 - a) Lack of a shared vision;
 - b) The difficulties associated with sustaining the existing delivery model having regard to resource availability;
 - c) The limiting effect of the prevailing delivery model on promoting relationships, citizenship, and inclusion;
 - d) An equity-safeguarding resource allocation model.

National Federation of Voluntary Bodies
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References

- **Constitution of Ireland** - Bunreacht na hÉireann (1937) and Amending Acts
- Department of Health and Children (2001) **Quality and Fairness: A Health System for You**
- Department of the Taoiseach (2009) **Transforming Public Services: Citizen Centred – Performance Focused** – Report of the Taskforce on the Public Service
- Government of Ireland (2008) **Scheme of Mental Capacity Bill 2008** To reform the law on mental capacity, taking into account the Law Reform Commission's Report on Vulnerable Adults and the Law
- Government of Ireland (2004) **National Disability Strategy** - www.justice.ie
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- Government of Ireland (1990) **Needs and Abilities: A Policy for People with Intellectual Disabilities**
- **Proclamation of Independence** (1916)
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- Government of Ireland (2006), **Towards 2016: Ten-Year Framework Social Partnership Agreement 2006 – 2015**
- Health Service Executive (2008) **National Strategy for Service User Involvement in the Irish Health Service 2008-2013**
- Health Research Board **National Intellectual Disability Database** – www.hrb.ie
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- **National Development Team for Inclusion (NTDi)** (UK) - working to promote inclusive lives for those most at risk of exclusion - <http://www.ndt.org.uk/home.aspx>
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- National Federation of Voluntary Bodies (2008) **Research Strategy 2008-2013**
- Northern Ireland (2005) **Equal Lives: Review of Policy and Services For People with a Learning Disability in Northern Ireland**
- United Nations (2007) **UN Convention on the Rights of Persons with Disabilities** <http://www.un.org/disabilities/>
- United Nations (1948) **Universal Declaration of Human Rights (UDHR)** <http://www.ohchr.org/EN/UDHR/Pages/Introduction.aspx>

Appendix 1 Reference Documents

An Overall vision statement could draw on such references as.....

Constitution of Ireland - Bunreacht na hÉireann

“Fundamental Rights

Personal Rights

Article 40

1. All citizens shall, as human persons, be held equal before the law. This shall not be held to mean that the State shall not in its enactments have due regard to differences of capacity, physical and moral, and of social function.”

Proclamation of Independence

“The Republic guarantees religious and civil liberty, equal rights and equal opportunities to all its citizens, and declares its resolve to pursue the happiness and prosperity of the whole nation and of all its parts, cherishing all the children of the nation equally

UN Declaration of Human Rights

“Article 1

All human beings are born free and equal in dignity and rights.”

UN Convention on the Rights of Persons with Disabilities

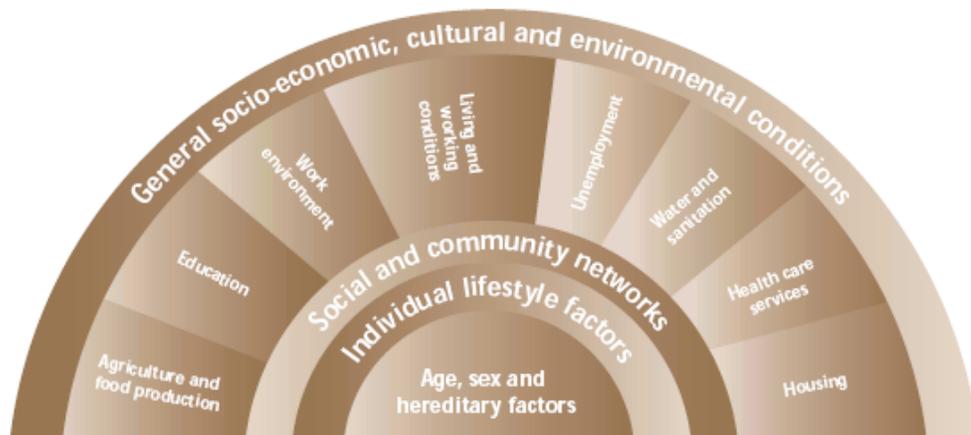
...recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,

...*Recognizing* that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind

Linking the factors that determine health

To develop an effective health system, the determinants of health, that is the social, economic, environmental cultural factors which influence health, must be taken into account. The diagram below sets out these factors.

Figure 1 **Determinants of Health**



- A vision statement needs to be cross generational 15-20 years and needs to be national and be relevant for voluntary and statutory bodies but most importantly needs to have relevance for people with disabilities and their families
- In times of economic crisis there is a particular need to provide value for money services which do not compromise quality nor impinge on the quality of a persons life.
- Policy decisions cannot be made in a vacuum of a vision statement.
- This policy would be an expansion of the vision for disabilities as set out in Section 33 of Towards 2016

Towards 2016: Ten-Year Framework Social Partnership Agreement 2006 – 2015 (Part III, The Lifecycle Framework, Section 33)

Section 33. People with Disabilities

33.1 Vision

The parties to this agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local community, free from discrimination.

To achieve this vision, the Government and the social partners will work together over the next ten years towards the following long-term goals with a view to continued improvements in the quality of life of people with disabilities:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;
- Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services;
- Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;
- Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential, and;
- Carers would be acknowledged and supported in their caring role.

National Federation of Voluntary Bodies

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability is a national umbrella organisation for voluntary/non-statutory agencies who provide direct services to people with intellectual disability in Ireland. Our 62 Member Organisations provide services to 22,000 people with intellectual disability and their families in the Republic of Ireland and employ 15,500 staff in a wide range of roles. Our members account for in excess of 85% of this country's direct service provision to people with an intellectual disability.

The services provided to people with an intellectual disability are founded on the values as set out in the O'Brien (1987) Principles of Inclusion, Choice, Dignity, Respect, Participation and Contribution. They are rooted in the rights based perspective that people with intellectual disability have the right to live full and active lives, and be active participating members of their own community.

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