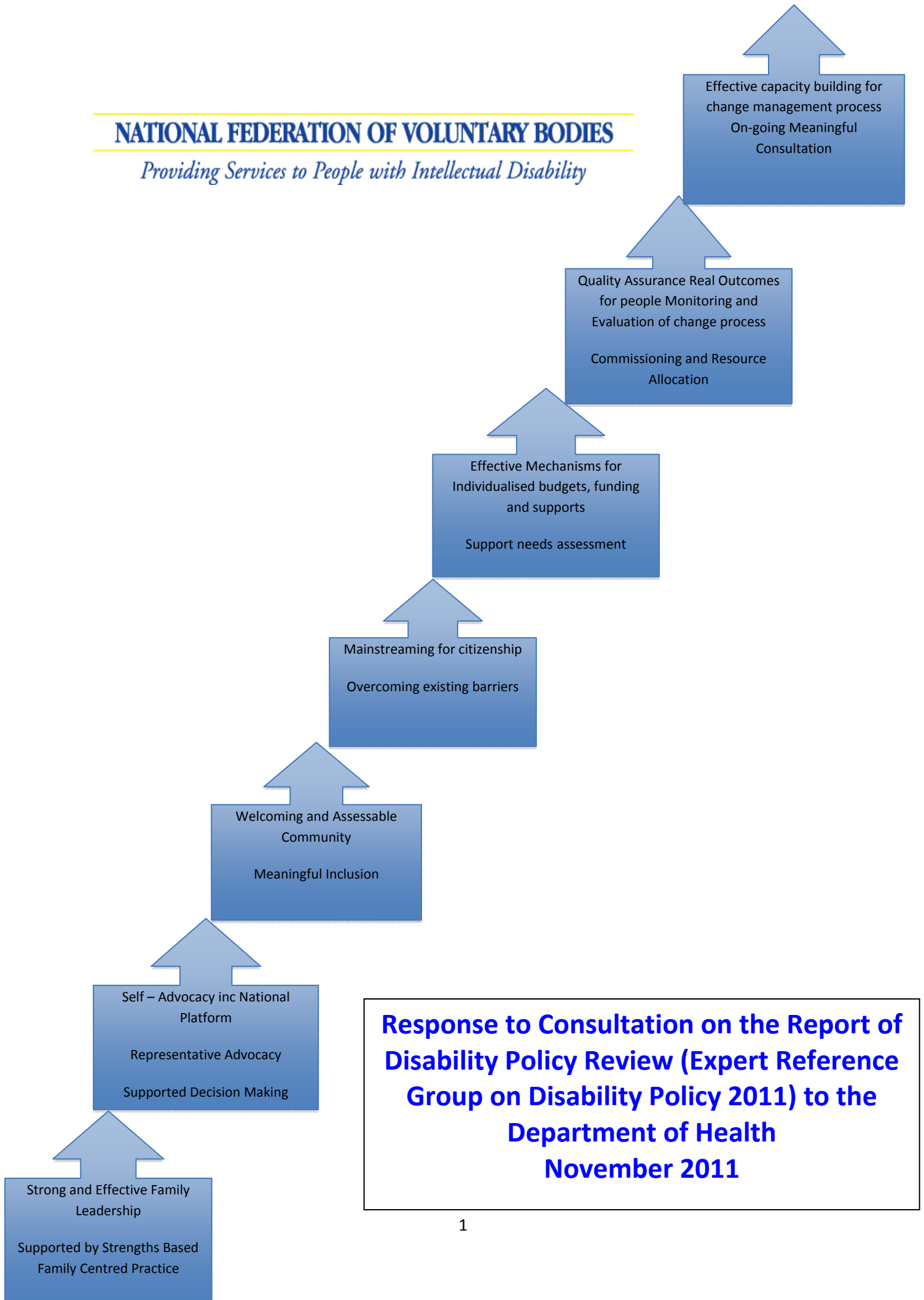

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability



**Response to Consultation on the Report of Disability Policy Review (Expert Reference Group on Disability Policy 2011) to the Department of Health
November 2011**

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1.0 Introduction

The National Federation of Voluntary Bodies is a national umbrella organisation for voluntary/non-statutory agencies who provide a wide range of direct support services to people with intellectual disability in Ireland. There are 62 Member Organisations who provide services to approximately 22,000 people with intellectual disability and their families and account for in excess of 85% of this country's direct service provision to people with an intellectual disability. This brief submission will focus on people with intellectual disabilities and people with autism and is set out in the following seven sections:

1. Introduction
2. Welcome the key elements of the policy proposals
3. How the National Federation of Voluntary Bodies membership has contributed to this reform
4. Infrastructure legacies
5. Comment on specific elements
6. Conclusions

The National Federation of Voluntary Bodies *Vision Statement for Intellectual Disability in Ireland for the 21st Century*, which is endorsed by its Board and General Assembly, outlines the vision as:

“Being supported to live a life on one’s own terms – Above all people have a deep and 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 and all its attendant possibilities for hope and fulfilment and to do so, to the greatest extent possible, on their terms. The implications of this simple truth will determine our actions on behalf of all citizens with Intellectual Disabilities”

The five core principles to drive this process are: **Self Determination - Friendships, Relationships, Inclusion, Equity, and Equal Citizenship**.¹ The values that guide the way we behave as a Federation are: **Integrity, Professional Conduct, Openness, Accountability, Person Centred, Quality Focussed, Commitment to Staff, and Voluntary Ethos**. The National Federation of Voluntary Bodies has developed five strategic priorities which form the basis of our Strategic Plan 2011 – 2014 which include: To provide guidance and leadership to our Member Organisations in the shaping and implementation of National Policy; To consolidate our commitment to continuous quality improvement and innovation; Staff employed and volunteers engaged by member organisations should be equipped with the competencies and skills necessary to implement national policy relating to people with intellectual disability; To deepen our relationship with key external stakeholders in addressing issues of mutual concern in meeting the support needs of people with disabilities; To comprehensively review the funding and financial issues affecting the sector. The National Federation of Voluntary Bodies welcomes the Policy Review given that the previous review was in 1990 with *Needs and Abilities* and substantial international process of change has occurred in the intervening 21 years. We consider that the National Federation of Voluntary Bodies Vision, Strategic and Actions Plans are consistent and coherent with the overall direction of the Report of the Disability Policy Review (Expert Reference Group on Disability Policy 2011).

2.0 Welcome the key elements of the policy proposals

The National Federation of Voluntary Bodies warmly welcomes the publication of this timely report which focuses on the inclusion and citizenship of people with disabilities. The Policy Review proposes an appropriately ambitious vision for the active inclusion of all people with disabilities as citizens in their communities. It is heartening to see this future policy for disability services underpinned by a strong vision and

¹ National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (2009) *Vision Statement for Intellectual Disability in Ireland for the 21st Century – Discussion Document*, Strategic Plan 2011 -2014, and Service Plan are at the following links: . [Vision Statement for Intellectual Disability in Ireland for the 21st Century](#) ; [National Federation of Voluntary Bodies Strategic Plan 2011-2014](#) ; [National Federation of Voluntary Bodies Service Plan 2011](#)

explicit values statements. In line with the National Federation of Voluntary Bodies vision statement we embrace the two goals of:

Goal 1 – Full Inclusion and Self-Determination for people with disabilities.

The underpinning principles and values: Citizenship, Control, Informed choice, Self-determination, Responsibility, Inclusion, and Participation.

Goal 2 – The creation of a cost effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities.

Underpinning principles and values: Equity, Person Centred, Quality, Effective, Efficient, Sufficient, Accountable and transparent.

However, we propose to amend the vision by including a focus on citizenship as set out below:

To realise a society where people with disabilities are supported to participate fully in economic and social life as equal citizens of this country and have access to a range of quality supports and services to enhance their quality of life and well-being.

The policy offers a real opportunity to consider the future support system that will best enable this vision. We robustly welcome and endorse many core elements of the extensive proposed Policy Review encompassing individual budgets and funding, individualised supports, mainstreaming, inclusion in community, better access to services, wider environmental accessibility all under effective governance.

Such reform is in line with the many progressive initiatives that have been developed by forward thinking, members of the National Federation of Voluntary Bodies in recent years which is in line with international practice and the requirements of the UN Convention on the Rights of Persons with Disabilities.² We welcome the recognition of disability as requiring response across all government departments and not solely a health issue. We specifically welcome the much-needed reform of the Needs Assessment Process and the small but importance reference to revised Duty of Care perspectives that needs to accompany individualised supports and how this shakes of the heavy weight of paternalism. This Policy Review is set in a wider framework of reform within Ireland, including the pending Capacity/Inclusive Citizenship Legislation, the establishment of the National Advocacy Service in January 2011, the recent publication of the Report entitled [Time to Move on from Congregated Settings – A strategy for Community Inclusion](#) the imminent [New Directions Personal Support Services for Adults with Disabilities Report](#) and the [National Housing Strategy for People with Disabilities 2011-2016](#), and underlying this the signing of the Convention on the Rights of Persons with Disabilities and its potential ratification in the near future.

Of central importance, we welcome the measures towards empowerment of and accountability to people with disabilities in the form of advocacy support. However, we are concerned at the absence of focus on Self-Advocacy, the power of Inclusive Research and the support for a national platform of people with intellectual disability. We are also concerned at the absence of a focus on family leadership and identify these as two key pillars to support the transition and reform and to ensure there is a transfer of power. Reform in other jurisdictions has been built on such foundations which would be strengthened by robust capacity/supported citizenship legislation which is compliant with the Convention on the Rights of Persons with Disabilities and is driven by a supported decision making approach. The central tenet of the policy reform will be the transfer of power to people with intellectual disabilities and their families. This Policy is an important mechanism to ensure that the principles underpinning the United Nations Convention on the Rights of Persons with Disabilities are incorporated into policies and programs affecting people with disability, their families and support people. Article 4.3 of the UNCRPD insists that people with disability and their families are actively involved in the drafting of policy and design of services.

The Implementation Plan must have regard to the realities of current service provision and provide clear direction to all concerned in the movement from the current service delivery models to the achievement of the new vision. It will need to encompass a major process of consultation directly with all stakeholders especially with people with intellectual disabilities, their families and service providers. Provision must be

² UN Convention on the Rights of Persons with Disabilities

made for the engagement and involvement of and communication with a wide spectrum of people, particularly those with significant disabilities many of whom are non-verbal and have complex needs. Engagement will need to go beyond token stakeholder representation on planning groups and also take into consideration all views about proposed service transformations. Building capacity through training and education among people with intellectual disability and autism and their families to enable them to partake fully in planning and decision making must be a priority. This will require significant commitment and investments. The Reforms proposed in the Policy Review are multi sectoral in nature and rightly call for a whole of Government approach. It is vital therefore that the implementation plan includes strategies for effective capacity building and monitoring and evaluation to ensure that the whole of Government approach delivers real outcomes that will ultimately improve the quality of lives of people with disabilities in Ireland. We propose that the Key pillars towards citizenship are:

- Voice of people with intellectual disability –a strong focus on advocacy leading to a national platform,
- Self-determination – individual life plan
- Strong and effective Family Leadership –
- Community inclusion and real participation
- Mainstream provision skilled up and accessible
- Individualised services and supports towards real lives
- Cross department responsibility for people with disabilities within a social model /human rights framework/ utilising the Convention on the Rights of Persons with Disabilities

3.0 How the National Federation of Voluntary Bodies membership has contributed to this reform

An obvious aspect of the Policy Review is the lack of distinction between what is actually working in service provision in Ireland and what needs to be changed. There is international recognition of innovative approaches in some aspects of provision in Ireland, however the Policy Review does not seek to analyse what lessons can be learned from this. Members of the National Federation of Voluntary Bodies are committed to progressive service provision and have introduced many innovative aspects that are detailed in the proposed Policy Review and have demonstrated that individualised approaches in Ireland can work. The learning from these innovations are also captured in the Genio Report which is entitled [Disability and Mental Health in Ireland: Searching out good practice](#). Members have also taken the lead in embracing accreditation with international quality systems that had a significant impact on improving the quality of person centred supports and had a substantial impact on the reorientation of the work of organisations to ensure that they do meet the needs of individuals. These initiatives have had a very positive impacts on people’s lives and have encouraged and empowered staff to look beyond their horizons and take appropriate risks to create opportunities for the people they support to lead meaningful lives. Members have benefited from the working with a number of key international change leaders in their bid to be genuinely person centred in their approach who report that Ireland is not alone on this journey of reform with most countries at different stages on change of this kind. Members have demonstrated innovation in a wide variety of areas including, family centred practice in early support services, supported employment, individualised supports, positive behaviour supports, Going to College Project, Seasamh, and embracing quality systems.

At the same time we acknowledge that there is the need for significant reform in key areas including the implementation of the Progressing Disability Services for Children and Young People Project, Moving on from Congregated Settings, and the New Directions Report, the latter which aims to provide a new approach to personal support services for adults with disabilities. In the implementation of the Policy Review we propose an appreciative inquiry approach that looks at what is working in the existing systems, especially the innovative and person centred aspects and what aspects need to change to create an understanding of how best to deliver the change required. We warmly welcome the new Policy direction, we fully recognise the challenges inherent within it and as National Federation of Voluntary Bodies we are ready to meet those challenges and have a proven track record of developing innovative solutions which demonstrate our ability to embrace new policy direction in a progressive and constructive way. We acknowledge that change is needed,

and that many of the proposed innovations outlined in the policy are exemplified by current work undertaken by Member Organisations.

4.0 Infrastructure Legacies

The opening section of the Policy review clearly identifies that current services need to be reformed, their direction having been accumulated over many decades without sufficient overriding vision or direction. It is important to note that there have been structural legacies which have hampered and impeded the voluntary provider sector in developing services in a more individualised community based manner. However, it is critical that a more detailed analysis of the interaction of factors that created these legacies is considered. The historical context needs to be understood in a broad way including the varied factors of: the paternalism and segregation of people with disabilities; the traditional block funding mechanisms which have been a significant impediment in the pursuit of individualised services; national agreements in respect of skill mixes and salary scales which have inhibited the sector as a whole and led to the over-professionalization of certain aspects of the sector; the interaction of the Government Departments, especially the Departments with responsibility for Health and Children, Education, Employment and Housing; the structure of the Civil Service; coupled with societal attitudes which alongside the actions of providers are all critical factor in understanding the absence of a disability policy for people with intellectual disabilities since 1990.

We recognise that the current system needs to change the centre of control from the Funders/Service Providers to the person who requires supports respecting their self-determination. While many of the comments of policy makers and politicians refer regularly to the need for service providers to change, there is rarely a statement of the shared responsibility of the funders to accept the call for true person-centredness. Many Service Providers have advocated strongly for a real change in service delivery, and indeed the Policy Review acknowledges that in certain areas service providers have been trying to evolve more individualised models; however this has not always been supported by Funders. Despite this structural legacy, organisations have and continue to develop innovative services, supports and programmes which have moved beyond the traditional models referred to in Part A of the Policy Review. We need to use the experiences of how supports are currently delivered to inform the future direction. We need to analyse what is working well within the sector and learn from that. In particular, it would be useful to consider the history of major system changes and interagency working in the Irish context.

However, the evidence for what people and families want warrants some caution. The feedback from the consultation process suggesting that 50% of people want to get a budget to choose and manage their own service (p.48), while encouraging, is from a limited sample. It is highly likely that many people and families are not that well versed in the concepts and implications of individualised budgets and self-managed provision. It would need more widespread engagement with people and families before coming to this conclusion. There is a real risk of moving ahead of people and losing buy in and ownership. Many families are probably just so worried about not losing what they have and could interpret the Policy Review as an attempt to undertake something less noble than the vision intends. There is a need to outline a process of more extensive engagement with people and families to ensure support for the Policy vision and direction is developed on a broad front. The difficulties facing the future direction of Policy and practice are significant. Financial conditions require that change takes place but the same financial realities will make it difficult to facilitate or fund these changes. In particular, extreme care must be taken to ensure the actions arising from the Policy actually deliver real outcomes to individuals and families.

5.0 Comments on Specific Elements of the Policy Review

The scope of the Policy is ambitious and seeks to address a very varied population yet has to remain sensitive to particular characteristics of need. We encourage a focus on the diversity to people with disabilities especially those with more significant support needs and is inclusive of all people with disabilities and such a review must be very aware of the needs of people who are less vocal and are not always represented at general consultation meetings. The structures proposed may work well for people who are in a position to self-

manage and navigate systems but may pose substantial challenges to others. It is critical that the Policy Review Implementation Plan focuses from the outset on prioritising people with high support needs.

The Policy Review is being undertaken in the context of very significant wider societal change and such issues need to be taken into account including: the availability of resources at a time of economic crisis, proper data for planning, for example there is an underestimation of the services and resources required for people assessed as having Autism Spectrum Disorder; the availability of jobs and employment for people with an intellectual disability and autism; the absence of a rights based legislative framework; public sector reform; public sector agreements like Croke Park which govern the flexibility of employment arrangements for organisations; the rollout of health reforms like the establishment and governance of Primary Health Care Teams; health and safety and the new regulatory environment; and the availability of housing and/or access to capital for housing as alternative to congregated settings.

This section is divided into seven sections, each sections includes a discussion of key issues under this heading and suggestions from the National Federation of Voluntary Bodies on each area. The seven sections are:

1. Family Leadership
2. Advocacy
3. Community
4. Mainstreaming
5. Individualised budgets, funding and support services
6. Commissioning and Resource allocation
7. Capacity building for change management process



5.1 Family leadership

Within this section on family leadership the following key issues are addressed:

- Family Leadership
- Family Centred Practice
- Information to Families
- Definition of Disability – Assessment of Need and Strengths Based Approaches.

5.1.1 Family Leadership

There is little reference to family leadership in the Policy Review which is regrettable, as we consider it one of the key pillars to support the depth of the reform proposed towards individualised supports. We recommend that this needs to be urgently addressed and developed within the Policy Review. We suggest that support for family leadership initiatives should be discussed as part of the wider advocacy strategy. Developing family leadership must occur in tandem with the individualization of services to ensure that such a transition is successful. We welcome the many recent family leadership initiatives, through the Family Focus project led by Brothers of Charity Clare, and LEAP both supported by Genio, the Partners in Policy Making and other programmes and in particular the links with MAMRE in Australia³. The Policy Review also has very little reference to siblings and this clearly needs to be addressed (only two references).

Families will require firm assurance that the integrity of the policy is not to increase the responsibility on families but to support them in promoting the citizenship of their son or daughter. There have been numerous concerns expressed by families that individualised funding can be more easily cut than funding related to staff with employment rights. The issue of aging carers must also be included. A process to ensure that the young people and adults will and preferences are respected and supported needs to be developed.

The National Federation hosted on family leadership entitled: [Shared Learning Event on Family Leadership in 2011](#), click on this link for more information. The National Federation Next Steps Project is addressing this under the action: Family Leadership & Involvement.

5.1.2 Family Centred Practice

Deeply embedded within our society are pre-conceived ideas and prejudices about people with a disability. People with disabilities are devalued and often expectations held are very low from birth to adulthood. People with disabilities need to be respected as unique individuals with the same right of access to citizenship in their community. This is a significant piece of work involving individuals with disabilities, families, service providers and Government Departments and should not be underestimated. Having a clear frame of reference as to how to engage with families and children across the life cycle lays the foundation for expectations and practice into adulthood. We are concerned that the overall focus of the Policy Review is much more developed for adults

³ For example see this parent developed website for the mid-west region - www.disabilityinfo.ie

and that similar depth of research has not been undertaken in relation to children. We propose that the Policy Review develops the section more on children and families.

The principle of the life cycle approach is essential and therefore, clarity is required on life cycle stages and transitions. The policy adopts the terms of the National Children's Strategy and identifies child centred and family oriented approaches as important principles. Within the context of normative childhood development, these represent the principles that children have a right to be listened to and the family should be considered as the primary and most effective environment for supporting the development of the child. However these principles represent limited models for practice in early intervention where the more evolved concept of a Family Centred approach offers an effective support paradigm to children with disabilities and their families. We consider the Family Centred approach as the essential foundation in ensuring children and adults are empowered and oriented towards mainstream supports.

Family Centred practice is an *"umbrella term for both a philosophy and method of service delivery"*. Specifically, it has been defined as being concerned with both the child's and families strengths as well as needs and involves providing support that integrates both natural and formal supports. Family Centred support is focussed on building family capacity. Child centred and Family Oriented approaches are different and represent a more traditional expert led model of intervention that has been prevalent for decades. Family Centred practice is a mainstream approach across a range of programmes that seeks to support children and families in diverse situations involving disability, protection and welfare, substance abuse, poverty/lack of opportunity and justice projects. Specifically, it has been defined as being concerned *"with the child's and families' strengths, needs and hopes and results in a service plan which responds to the needs of the whole family"*. Family centred service delivery has been defined as *"recognising the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses upon the strengths and capacities of these families"*⁴

While a focus on the centrality of family capacity or strengths building perspective is central there are various emphases on different aspects of family centred practice. Some examples include focusing on everyday environments and the role of natural supports; how to train practitioners in family centred practice, relationships between professionals and parents, provision of accessible information to parents and families. A further key aspect is that the rationale of the approach is based on a firm commitment to empowering and enabling families as the key supporters and facilitators of their family member and recognition of the importance of avoiding any de-skilling or dis-enabling of parents through an over-professionalization of supports. A significant challenge to efforts to work within a Family Centred approach is to support professionals to move from the "professional as expert" paradigm often central perspective in professional training courses to a "professional as enabler/partner" position, the keystone of Family Centred practice. Evidence of Family Centred approach in practice include: using a key worker model whose role is to blend multiple inputs, being life focused and not service focused, beginning with the lowest level of intervention necessary in the early stages and exploring a wide range of possible interventions including peer interventions, using an individualised strengths based approach, and not a deficit model, and providing support to the family and not just the child. A useful theoretical model has been developed that allows service providers to explore where their service efforts are situated along the continuum set out below:

- *Professionally Centred: Professionals see themselves as experts who determine family needs*
- *Family allied: Professionals enlist families to implement intervention under the guidance and tutelage of professionals.*
- *Family focused: Professionals provide advice and encouragement to families on the basis of their choices and decisions*
- *Family centred: Professionals view themselves as agents of families who strengthen existing and promote the acquisition of new skills*⁵

⁴ The following references are used in this section and further information is available on request: Rosenbuaam King, Law, and Evans (1998) Cole (1995), Carpenter (1998), Dunst & Trivette (2009), Greene (2004) Viscardis (1998), Viscardis (1998), Viscardis (1998), Allen and Petr (1996), Moore & Larkin (2005), McConkey; Dunst & Trivett (2009) Dunst et al, (2002) and Guralnick.

⁵

It is a feature of some current policy formulation e.g. the Transformation Programme in Early Intervention Services, to use the different terms interchangeably and without consistency. This is also evident in the Policy as written. So, for example on p.85, the key principles are described as (1) Child Centred and (2) Family Orientated – whereas in the very next section 12.6.2 on p.85, the term used is ‘Child and Family Centred’. This leads to confusion as there are fundamental differences between *a Family Orientated* and *a Family Centred* approach. The former tends to be a more traditional approach in which family inclusion may, in reality, be determined by professionals. This can lead to medical models of intervention emerging which is not in support of the Policy Vision. It is the view of the National Federation of Voluntary Bodies that there is an insufficient commitment to Family Centred practice within the Policy Review and that in the amalgamation with various services there is a serious risk of returning to a medical professional led model focused on treating impairments. We recommend that a Family Centred approach is embraced as a core element of the Policy Review.

The focus changes as the child moves from childhood to adulthood. A key concept for describing how families change and adopt their role as children develop is that of “evolving capacity” as outlined in the UN Convention on the Rights of The Child (1989) Article 5 and Article 5 of the UNCRC, we suggest that this moves from the focus on the family to the focus on the young adult as follows:

- Child and Family
- Young adult and family
- Adult - Person centred planning – and Family involvement as determined by the person themselves.

In order to honour this, parents and others have the responsibility to continually adjust the levels of support and guidance they offer to a child, effectively enabling children to increasingly participate more in the realisation of their rights. In the case of very young children, the family are the decision makers. As the child ages and moves through youth and adolescence, there is a natural transition in decision making towards increasing autonomy by the growing child. Having a clear frame of reference as to how to engage with families and children across the life cycle lays the foundation for expectations and practice into adulthood. In the policy there is no distinction made between children of significantly different ages. However, there are many significant differences in the dynamics of the child in the family across the life cycle. Understanding these differences is important and will assist clarification of the theory of support and frame practice implications more specifically. This in turn will permit a clear definition of quality and assist the design of measuring outcomes. We strongly suggest that a distinction be made between families with young children from birth through pre-school and early school years and children who are of established school age, young adolescents or indeed approaching adulthood. Ultimately the life cycle must consider the emerging role of an adult in the family and increasingly an older person with siblings. We propose that Family Centred practice is the foundation for person centred practice.

The National Federation hosted a major International Conference with included presentations on Family Centred Practice with Carl Dunst and John O Brien. For further information the link to the papers and presentations is at: http://www.fedvol.ie/Challenging_Times_Ensuring_Values/Default.1698.html

5.1.3 Information to families

The policy review recognises the importance of information to families (page 87). The National Federation of Voluntary Bodies has developed evidence based best practice guidelines to guide professionals in the communication of the news of a child’s disability to the family. The dissemination of best practice guidelines which promote the dignity and worth of each child as an individual, from the very first communication, is of vital importance for mainstream professionals and those working in disability services, who inform families of their child’s disability; and to receive training on this process. There are over 27 different disciplines who are involved in informing families of their child’s disability from across hospital, community and disability settings, depending on the timing and context of the diagnosis⁶. The way in which families are informed of their child’s disability has an impact on parent-professional relationships thereafter and it is vital to begin this relationship on the right footing and to build trust. *“Good disclosure practice prevents much distress for parents, and can*

⁶ <http://www.informingfamilies.ie/fileupload/Informing%20Families%20Consultation%20and%20Research%20Report.pdf>
<http://www.informingfamilies.ie/information-for-professionals/evidence-based-good-practice.106.html> last accessed the 17th.11.11

*form the beginning of positive parent-professional relationships, facilitates the attachment process, and when combined with family support services over the first years, reduces levels of anxiety and stress.*⁷ The Informing Family Guidelines are on the National Federation website, including the report of the implementation of the Guidelines in a Pilot Project in Cork and are available at the links below. Temple Street Hospital has just recently begun the process of implementing the Policy Guidelines. We propose the inclusion of the Informing Families Guidelines in the Policy Review and seek their national roll out.

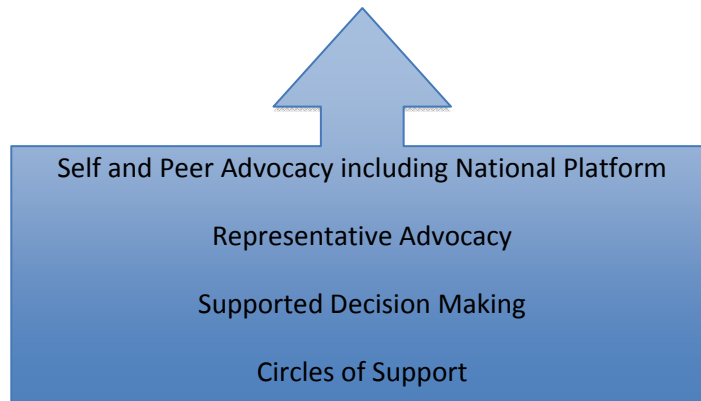
5.1.4 Definition of Disability – Assessment of Need and Strengths Based Approaches

We warmly welcome the statement that the Assessment of Need (AON) under the Disability Act 2005 needs to be revised given that it does not correspond to a ‘needs assessment’ as understood in the wider, international disability sector. The Policy proposes that the definition of disability will be that of the Disability Act, yet acknowledges that the AON process needs to change. However, we propose that this creates incongruence and that the definition also needs revision to focus on a person’s strengths and abilities and the environmental barriers to participation. In addition there is confusion how this definition relates to children and the interpretation under the Progressing Disability Services to Children and Young People. We are concerned that there are very different approaches around the country at the moment with some regions using the current AON Process as the access point to services and others directly accessing support services.

It is of significant concern that Assessments of Need (AON) are intrinsically ‘deficit focused’. Therefore it is reasonable to assume that any family engaging with the process of assessment will be forced to accentuate levels of need in order to secure the best possible support package. Consequently, we could be setting up a situation whereby families insist on the professionalised approach to supports in order to remain on ‘priority’ lists going forward to adult services for example choosing traditional supports over home sharing. Another area of challenge with regard to AON is where a citizen with disability could actually be penalized for having a rich network of family and friends around them. This poses a question why do people not develop natural supports - is there a reason for this? Is it that families over time depending on services learn to lose belief in their own competence, ability and expertise or learn they need to get into a crisis in order to receive support? The reality is that to have a good life is not just realised through the activities of service providers and paid supports but paid and unpaid natural supports working together and complimenting each other. It must have at its core individuals, families and community. This work needs to be rewarded and taken into account in any assessment of need process. We recommend that it is useful to consider an Assessment of Need process that incentivises individuals, families and communities who have developed strong networks of support. One possible way to do this is to attach funding to maintain such networks and continue to nurture and strengthen the work of families and communities. A suggestion would be to look at initiatives/projects that would pilot some exploration work in this regard.

Questions have arisen about when and by whom AON are completed and what is the interface between the visionary planning process for the person and the AON which require further elaboration. One of the significant challenges that needs addressing is the notion of an Assessment of Need and the development of a support plan before engaging with the support providers. Planning is essentially a process of facilitating an emergent vision and requires repeated problem solving and doing involving all the resourcefulness and creativity of the informal and formal support network. Planning, doing, learning and revisiting the vision is unpredictable as people and their support needs change as their capacities grow or diminish. Currently, the Policy Review reads as if the planning process is completed and that the provision is procured to implement the plan. This is concerning and may not provide the flexibility required. In addition the experience particularly with regard to children’s early intervention services has been that following Assessment of Need there were little resources to support families transition and develop recommendations arising from the AON.

⁷ Cunningham, C. (1994) *Telling Parents their Child has a Disability*. In Mittler, P. & Mitter, H. (Eds), *Innovations in Family Support for People with Learning Disabilities*. Lancashire, England: Lisieux Hall.



5.2 Advocacy

Within the section on Advocacy the following key issues are addressed:

- Self and Peer Advocacy
- Representative Advocacy
- Legal Capacity Legislation - Supported Decision Making
- Circles of Support

5.2.1 Self and Peer Advocacy

The focus of the discussion of Advocacy in the Policy Review relates more to formal Representative Advocacy, which while of great importance, we propose needs to operate alongside, Self and Peer advocacy and not in isolation. The Inclusive Research Network (IRN) is a group of people who come together to do research or talk about research that is about people with intellectual disabilities. IRN, who is supported by the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability (NIID) at Trinity College Dublin, have undertaken a number of research projects (which are available to download at the links in bedded):

- [Where we Live](#) Report
- [Relationships & Supports Study](#) Report

The Inclusive Research Network is doing Advocacy through research, and has gained an international reputation for this work. It demonstrates the power of people with intellectual disability speaking to each other to speak up for themselves.

Many Member Organisations of the National Federation of Voluntary Bodies actively support advocacy programmes within their organisations. In addition a number of organisations are actively encouraging decision making by people supported by the organisation in the running of the organisation. The National Federation of Voluntary Bodies recently held a [Sharing Innovative Learning Event on Participating in Decision Making](#) and Members presented Participative projects which can be found in the this link. [Rob Greig](#), NTDi (previously with Valuing People UK), was the key note speaker, and talked about the National and Regional Platforms that were established as part of the reform of services and supports to people with intellectual disability in the UK. He outlines their essential role of changing the power balance and strengthening the voice of people with intellectual disability in the change process. The presentations of Advocacy supported by Member Organisations, included examples of personal, organisational and regional advocacy and to some extent community advocacy. We recommend the expansion of Self and Peer Advocacy within the Policy Review as an essential part of its implementation in supporting the self-determination of people with intellectual disabilities at a personal level and as a Network with whom the Department of Health and Children and others could consult. As stated in the Convention on the Rights of Persons with Disabilities it is important that disabled people's voices be included not just at the level of individual services, but also at the policy making level. This involves building the capacity of self-advocacy groups to participate in and contribute to policy and systems development. We support the establishment of a National and Regional Platform of Advocates.

5.2.2 Representative Advocacy

We strongly welcome the central role of advocacy proposed within the Policy Review and anticipate that this role alongside Self-Advocacy, Peer Advocacy, Supported Decision Making generally and Circles of Support specifically are the key mechanisms that will shift service provision in Ireland from its paternalist roots to a progressive person centred supports for real lives. In this vein, considering the dimensions of advocacy as a disability support, it is important to recognise the potential of advocacy to act as a less restrictive alternative to the imposition of guardianship or substitute decision-making. In addition, future policy on advocacy should be framed by human rights principles contained in the UN Convention on the Rights of Persons with Disabilities (CRPD) especially principles of Access to Justice (Article 13) and Legal Capacity (Article 12). We encourage that the National Personal Advocacy Service is equipped with its full statutory powers. We welcome the recent proposed repeal of the Criminal (Sexual Offences) Act 1993 by the Law Reform Commission and the removal of such “status” based legislation and the door it opens to focus on protection of all rights including the rights of protection and the right to expression. The National Federation held an event on the [National Advocacy Service entitled Advocacy in Ireland Changing Times](#) in February 2011 which provided information and insight into the changes to advocacy in Ireland.

5.2.3 Legal Capacity Legislation - Supported Decision Making

We consider the conclusion of the impending Legal Capacity Legislation that is compliant with the Convention on the Rights of Persons with Disabilities, as a key component in implementing individualised supports towards a real life. This will reinforce the focus on the *will and preferences* of people with intellectual disabilities enforce their self-determination and the move away from paternalism and strengthen the move to supported decision making in all its forms. Such legislation should also provide for a continuum of supports for decision-making to be available to individuals, including advocacy support, reasonable accommodations regarding information and decisions, accessible information and decision-making processes, and the use of supported decision-making networks (including representation agreements as used in the British Columbian province of Canada).

5.2.4 Circles of Support

We warmly welcome the focus of Circles of Support in the Policy Review. The use of Circles of Support has been demonstrated by the [Transitions to Social Inclusion](#) Pobal Project led by Brothers of Charity Roscommon and the [Family leadership what, why how?](#) And also Family Focus projects led by Brothers of Charity Clare. A wide number of organisations increasingly use this model of support.

The Next Steps Project is addressing these issues under the work programme of: User Involvement – decision making and advocacy which includes the development of a training tool on rights awareness and development.



5.3 Community

Within the section on Community the following key issues are addressed:

- Inclusive Community
- Role of Parent and Friends Organisations
- Volunteering
- Community Readiness and Attitudes

5.3.1 Inclusive Community

We welcome the focus on inclusive Communities, and building relationships. Member organisations have invested significantly in building strong community links. We see the primary role of support staff as community connectors. In 2007 the National Federation of Voluntary Bodies produced a very informative Report entitled *People Connecting*⁸ which discussed the barriers, incentives and solutions to community participation & inclusion of people with intellectual disability by people with intellectual disabilities. It will shortly be launching the *Real Life Connections Guideline* (2nd December 2011) prepared by the Volunteering and Community Inclusion Sub-Committees and which is accompanied by a video made by a young woman and a member of the Committee who radically changed her life to be actively living and working in her own community.

5.3.2 Role of Parent and Friend Organisations

Most of our Member Organisations grew up out of community and are deeply embedded in community. We are concerned that the section on community participation may underestimate the role voluntary provider organisations play in supporting community connections and participation and the community foundations that underlie many voluntary providers. It is appropriate that the aim should be to pursue the normative root rather than seek specialist services as a first option. However building capacity in communities presents a dilemma if the existing Parents and Friends organisations are to be ignored. Many Voluntary Providers have long traditions as “Parent and Friend” organisations with deep roots in local communities. While there may be much untapped potential in many cases there is a latent resource which is organic and not easily replicated. Serious consideration needs to be given to how communities can be mobilised and empowered without alienating existing grass roots structures. Existing providers should be required to prove their community credentials. We recommend that new providers should be required to have community credentials.

5.3.3 Volunteering

The Policy Review does not appear to recognise the value and role of volunteers in the lives of the people with intellectual disability supported by organisations, and the mechanism for coordinating and harnessing the volunteer involvement. This is an area which has been strongly developed and supported by many voluntary service providers; it's a huge reservoir of goodwill and resources for people and should not be overlooked in any reconfiguration and leads in many instances to meaningful and sustained relationships. We propose this is a key area to explore in the Policy Review and although related to is separate from natural supports. In 2008, the National Federation published an important report on volunteering entitled [Volunteering in Intellectual Disability Services in Ireland - Supporting People to Live the Life of their own Choice in their own Community](#)

⁸See http://www.fedvol.ie/_fileupload/People%20Connecting%20-%20June%202007.pdf last accessed 18.11.11

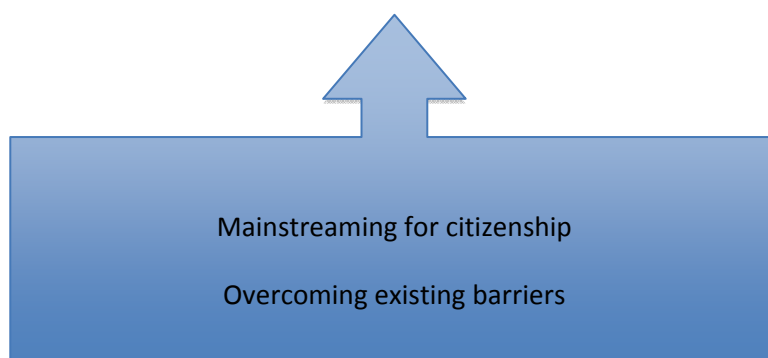
which indicates that the economic value of voluntary input in the section is €50million per annum (National Federation Member Organisation Survey October 2011). A report entitled [People Connecting](#) incorporates the findings from Consultative Workshop on the Barriers, Incentives and Solutions to Community Participation & Inclusion of People with Intellectual Disability.

5.3.4 Community Readiness and Attitudes

Community readiness to embrace and include people with intellectual disability as well as the openness and capability of mainstream services is a significant challenge to the implementation of the Policy Review. Social inclusion and citizenship is a two - way process. Barriers to social integration are often economic and cultural, Member Organisations report people with intellectual disability being marginalised and stigmatised. The expertise in the intellectual disability sector could be further developed to support people living in the community, to engage and prepare communities and also enable and empower mainstream provision like schools and training providers, primary care teams and hospitals, employment and housing providers to adapt, transform and become accessible, inclusive and supportive to people with intellectual disabilities and autism. For the purposes of the implementation of the Policy Review 'community' could be better defined and structures and organisations on the ground could be strengthened to embrace mainstreaming and inclusion. However, currently the community and voluntary sector is being cut back and not expanded to take on new roles and responsibilities.

Member Organisations are increasingly focusing on community inclusion training, for example KARE have FETAC accredited course on Community Inclusion and Facilitating Friendship Development which are inclusive training modules for people with intellectual disability and staff.

The National Federation Next Steps Project is addressing this under the action Mainstream & Community Involvement and the action Identifying Barriers and Solutions.



5.4 Mainstreaming

Within the section on Mainstreaming the following key issues are addressed:

- Mainstreaming and citizenship
- Mainstreaming the challenges
- National Disability Strategy
- Separation Health and Personal Social Services
- Education
- Employment
- Lifecycle - Aging population

5.4.1 Mainstreaming and Citizenship

We fully support the mainstreaming of supports to people with disabilities in all policies and actions the Government undertakes balanced with the need to develop specific actions plans, supports and services when necessary to address particular topic areas relevant to all or particular groups of people with disabilities. Successful mainstreaming will require the inclusion of people with disabilities and all relevant stakeholders in decision-making, to ensure that the needs of all types of disability are met in policy. It is important to ensure that the definition of mainstreaming encompasses firstly, the provision of supports to enable people to access generic services and facilities, secondly, the provision of reasonable accommodation by mainstream providers to ensure full access and participation and thirdly, modifications or adaptations of mainstream services and facilities themselves. All three aspects of mainstreaming are equally important and while the latter will require more long term planning and design (including the application of the principles of Universal Design), it should not for this reason be postponed as too costly. Mainstreaming is a central mechanism to realise the proposed Policy Review Vision and requires all Government Departments to commit to an approach of tailored universalism. It will be necessary to have in place a very good framework of review, evaluation and monitoring and a strong commitment to ensuring this takes places. Otherwise the result will be a good policy document but little evidence that stakeholders are working to this policy in practice and reality resulting in little change for people with disabilities and their families.

5.4.2 Mainstream – the challenges!

Despite our commitment to mainstreaming we know from experience that there are significant challenges to be overcome. The experience of people with intellectual disability in accessing mainstream services has been one of exclusion, especially in relation to mainstream Early Support Services, Mental Health Services, and Child Mental Health Teams. In addition accessibility is a central issue. Mainstream health services are often denied to people who have a disability simply because they have a disability. On the other hand there has been great support from many local authorities in relation to housing for people who have disability. We propose that for individual supports to progress mainstreaming will require a societal buy-in and an acceptance by the mainstream services that people with disability, particularly those who have an intellectual disability, have the right to avail of mainstream services.

The current policy on mainstreaming has made a difference to some people's lives; however, it has been inconsistently applied throughout the country. Examples of this can be seen in the area of education and training. The transfer of the vocational training budget from the Department of Health to the Department of Enterprise, Trade and Employment never reached its goal of giving people with disability the opportunity of

accessing training courses in FAS training centres. This has a negative impact on people's lives and reinforces inequality in accessing resources. On the other hand, the supported employment initiative has made a difference in ensuring that people with a disability can access the labour market and secure good paid employment.

It is vital that these services have people employed in mainstream services have the appropriate attitude, training, knowledge and skill sets to support people with an intellectual disability. Mainstream services must be resourced, developed and evaluated on their ability to meet the needs of everyone. We consider that consultation with the mainstream services to identify the steps required towards inclusion will be essential and will require a skill sharing between the disability support services and mainstream services to ensure effective access. There is also a real fear of the dilution of services especially in these financial circumstances. The whole issue of primary care is an example of the many areas that need to be developed before there is any drastic restructuring of disability services. In order for people with intellectual disability to avail of appropriate care within primary care services, as indeed they should be able to do, there must be radical improvements within the teams—to include local-area access to appropriate team members. The Policy Review implementation requires the proper funding of the primary care network.

The vision of the policy to detangle Housing, Training and Employment and personal social services from the Health Services, whilst understandable, it may have the potential for a lack of an holistic approach with each individual Government Department being responsible only for their area of remit. With the current Governmental structures, there must be assurance that the full range of holistic care and supports will be accessible to those who need it or will there be services and supports that fall through the gaps because of lack of funding, resources and or expertise/knowledge within the relevant departments.

5.4.3 National Disability Strategy

The National Disability Strategy was launched by Government in September 2004 with the overall aim of supporting equal participation of people with disabilities in mainstream society. The implementation of the National Disability Strategy is the agreed focus of disability policy under the Partnership Agreement Towards 2016 (T2016). What this means is that disability policy and programmes relevant to the lifecycle framework for people with disabilities will be progressed through the National Disability Strategy with particular expression being provided through the six Government Department Sectoral Plans. Mainstreaming and Citizenship are central objectives of the new policy vision and requires all Government Departments to commit to the achievement of these objectives. The new Policy Vision would therefore in our view be best progressed in the context of the National Disability Strategy

5.4.4 Education

There are varied reports from Member Organisations in relation to the experience of children in education, some Members report that "increasing numbers of children with disabilities are returning to special schools" while this does not reflect the situation in other Organisations which have increasing numbers of children with disabilities attending mainstream secondary schools. It is not clear that dual enrolment is a desirable option for children. The use of special schools as a resource to support inclusion in mainstream schools, also cited, is likely to be a more effective way to support inclusion. Suggesting that there needs to be appropriate protocols between Education and Health Services (p.113) after some thirty years of similar proposals highlights the challenge of operating a "seamless" support structure in an interagency arrangement. The description of the role of Education and Special Schools contains a whole subtext about variable levels of inclusion that should not be glossed over. There is concern that the commitment to Mainstream Education is not strong enough within the Policy Review. The future role of special schools in the context of a mainstreaming policy needs to be examined further. There are a number of initiatives for people with intellectual disability and autism to attend third level education and a number of inclusive mainstream initiatives. See the Going to College Project, NIID and a number who are providing a "course coach", this person could support the person to participate in the course of their choice. Real access to mainstream services requires that people are provided with real supports that facilitate their inclusion at their own pace. We recommend a review of the HEA guidelines to include people with intellectual disability in accessing third level education. We consider a stronger commitment is made to Lifelong learning.

5.4.5 Employment

Two reviews of FÁS carried out since mainstreaming was introduced in 2000 suggest that the integrated employment service has seen disability expertise dispersed and supports for individual disabled jobseekers diluted.⁹ Critical to the reform is the necessity to plan how to use existing knowledge on disability supports to ensure it is utilised to best advantage. This requires review and monitoring systems to be in place to check if systems are working for their intended outcomes and to implement necessary reforms for effective systems. In meeting the supported-employment needs of people with intellectual disability. Several disability services have developed effective supported employment services through disability awareness programmes and liaison with local employers.

5.4.6 Life-cycle - Aging Population

People with intellectual disability are now living longer in line with the general population. We recommend that older people should feature throughout and within each action area acknowledging the need to plan for the ageing population of people with disabilities, similar to the general population. IDS TILDA will assist in guiding policy development in this area in the future. Planning and coordination across government agencies, service providers and other relevant stakeholders is urgently needed to ensure this population group are able to lead healthy, active and fulfilling lives as they age now and into the future. A poor interface between disability and aged care provider systems and public policy, eligibility requirements for services (remove the chronological age as a marker for entitlement to services and replace it with need criteria), funding, service provision and service designs that do not yet recognise that some people with intellectual disability experience ageing earlier, that their needs change with ageing and that service systems need to be redesigned. Already we are seeing that ageing carers find it difficult to continue to provide support, and many now need assistance themselves. Similarly, the life cycle framework needs to acknowledge ageing carers and children with disabilities as carers. We endorse an "ageing in place" approach.

⁹ Conroy P and Brennan A (2002) Disability Customer Survey 2002. Dublin: FÁS recorded some concerns of FÁS staff about their capacity to serve clients with disabilities effectively, unless former NRB staff were available. Similar concerns were recorded in the Bearing Point Review of Vocational Training Provision for People with Disabilities in Ireland. (Dublin: Department of Enterprise, Trade and Employment 2004) where some front-line staff said their disability training had not adequately prepared them for the practical realities of dealing with people with disabilities.



5.5 Individualised budgets, funding and support services

Within the section on Individualised Budgets, funding and supports the following key issues are addressed:

- Individualised Funding
- Safeguarding
- Duty of Care
- Key worker and complex system - Who holds person story?
- Moving on from Congregated Settings
- Over-professionalised - Skill mix
- Technology

5.5.1 Individualised Funding

We welcome the move to individualised budgets, funding, and supports identifying this as a critical step towards a just and equal society where supports are in place to ensure that people with disability can access the same opportunities and services as people who do not have a disability. We acknowledge that effective systems to undertake this process are the lynchpin. We acknowledge that not all individuals or their families may want to take on complete control and governance of their funding but the option should be there. It will be important that there is a process in place to empower individuals and strengthen family's capacity to do this. There needs to be recognition that there is a difference between individualised budgets and individualised supports. We realise that having individualised funding will not, in itself, lead to their being support that people require, so they must be seen as just one element of the reform process. We are concerned that that individual budgets may be even more easily be reduced because of 'limited resources', than the current cutbacks to service organisations, despite their annual service agreements. In discussions with parents they have expressed their concern that individual supports could be the first to be cut and that a system of guarantee will be required to allay these real fears. It must be remembered that although the block funding system makes it difficult to "unbundle" the budget for an individual, it is still possible to provide individualised supports to people because individualised supports and individualised budgets are not the same. Sometimes within block funding the budget allocated for new developments allows for supports to be provided to a larger group of people than if the budgets had been individualised. There is a need to examine the relationship between the mechanism of funding and the control and choice of an individual and vital to learn from the experience of other jurisdictions of what has and worked.

Two events that the National Federation hosted on Individualised Supports were entitled: [Towards Personalisation in Disability Support: Lessons for Ireland in Reforming the Disability Support Sector](#) and: [More Choice, More Control - Supporting Citizenship through Individualised Supports](#) full information can be found at these links.

The National Federation Next Steps Project is addressing this under the action Reconfiguration, Individual Budgets and Services. One of the initiatives of the Next Steps project by an organisation is to aim to address emergencies in the next year without reverting to placement in a congregated setting.

5.5.2 Safeguarding

The UK experience, highlighted by Professor Hilary Brown advises that initially when individualised funding and supports were set up in the UK that there was little focus on safeguarding. However, in the recent revisions of the UK policy this has become a key element. An example is listed in the links below.¹⁰ The debate in the UK and the recent consultation by the Law Reform Commission in Ireland on Sexual Offences and the Capacity to Consent and the Audit of Client Protection highlights the need to consider a national Adult Safeguarding policy that has legislative force.

¹⁰ See <http://www.idea.gov.uk/idk/aio/25765507> last accessed October 2011

5.5.3 Duty of Care

A small but very pertinent reference is made in the Policy Review on the changes that will be required in the understanding of Duty of Care within an individualised framework. This is the heart of ensuring individualised services are directed by the person's will and preferences and not by organisational considerations. We welcome the statement: *"international best practice in disability services... is to move away explicitly from a medical model of care to a social model of support, with the emphasis on maximising self-determination, community participation (inclusion) and equal citizenship....This change in orientation and relationship in the area of disability services requires fundamental change in the understanding of the duty of care that is typically held, where the client is viewed as a dependent and passive recipient of services."*¹¹ We consider this a very important piece of the policy and needs to be explored to secure legal agreement and should never be used as a reason to restrict people's choices. We need to find a way of meeting individual rights and duty of care. We need to highlight the fact that this is an issue for service providers and there is legality that needs to be recognised.

5.5.4 Key worker - Who holds person story?

Planning is a process of facilitating an emergent vision for the person and how they want to live their life. It requires repeated problem solving and involving all the resourcefulness and creativity of the informal and formal support networks. Some organisations suggest that the apparent demarcation between planning and doing as it appears in the Policy is a potential fault line, yet at the same time, services that have developed individualised supports identify it as critical that this visioning plan need to be developed free of the constraint and limits of the service provider funding, allowing for a broad view of natural and other supports in the melting pot of the vision. It also potentially increases the ownership of the story by the person and their circle of support. The experience of supporting individualised arrangements is that they require very significant effort to maintain the identity of the person in a system that is constantly prone to compartmentalisation. The risk of fragmentation of future support arrangements is substantial and requires clear plans of how to ameliorate the impact of the fragmentation for the person. Successful examples are the most potent evidence and the most convincing way of communicating the benefits, particularly when people and families are champions of their own arrangements but it is often a slow process. It is important also to provide adequate resources and training to build and strengthen capacity of individuals and families whereby the process is guided and directed by them. This is largely a new departure for individuals and families as within current service provision person centred planning is largely initiated and directed by service providers. The independence of this process cannot be over emphasised as the person facilitating this must be independent of the funding provider and also service provider. However this is an area that will need to be piloted and explored to ensure positive outcomes for individuals and families.

We propose that it is critical for the Policy Review to consider the risk of fragmentation and to identify safeguards that can be put in place. The move to individual real lives creates the shift from one support provider to a multitude of supporters and actors in the person life which is to be welcomed. As people will purchase or receive supports from an array of providers, no single entity will be responsible for holding the person's story of their vision and plan. The only person who will be in a position to do this is the person or their advocate and circle of support. This is a constant challenge in single organisations but the capacity to see the person's full life vision at least puts it on the agenda and may prompt a response to address this. The diagram on Page 123 offers a foundation on which to build an additional dimension that addresses the challenge of supports coordination. The further up the pyramid, the more probability of complexity in support arrangements and the greater the necessity of reducing the number of people and providers and departments that are involved with any person or family in the first instance. Currently, this extra dimension is referred to at various stages in the policy as an issue for people with multiple complex needs. The less the person depends on supports to hold their story, the more empowered they are likely to be. However, it is really important to face up to the vulnerability this will present to people for whom self-managing across programme boundaries is a serious challenge. Mechanisms of supporting the person's vision such as Circles of Support can find it hard to influence the formal system so the challenge of fragmentation does need to be worked out. The solution of having link workers, key workers or coordinators may be effective in some cases, it will require that these roles

¹¹ Bonardi, A. (2009) *The balance between choice and control: risk management in New Zealand Intellectual disability services*. Fulbright: New Zealand

have real authority to act where a lot of issues compete for attention. Support will be required to deal with the fragmentation challenge.

5.5.5 Resource Allocation

The report sets out the governance framework to create “a high quality, cost-effective, responsive and accountable system” which is very positive in terms of the key elements to such a framework. We welcome the feasibility study undertaken by NDA with Member Organisations in researching the international environment in respect of resource allocation models. In terms of allocating resources, individualised or self-directed budgets is only one piece of a framework which requires each and every part to be working in unison including the processes for procurement and commissioning. There is concern that the capacity does not exist within the HSE to manage the planning, procurement and commissioning of services and the experience around the Assessment of Need process for the 0-5s needs should inform the design process.

5.5.6 Moving on from Congregated Settings/ Reconfiguration of existing Services

The majority of segregated service provision is concerned with People with Intellectual Disabilities, and the report identifies this area as the one where significant resources are going and with generally poor results. Change will therefore impact most on this population. It has been well documented that while community-based housing can achieve better outcomes in terms of quality of life and community participation for disabled people, this in itself is not sufficient. There is a concern that by mandating four person residential units that this will be considered the norm and not the maximum number of people as set out in the report. Also there is the risk that institutional group practices could be replicated over individual choice. Appropriate housing to accommodate people is required. It is acknowledged that housing and where one lives has a profound impact on ones quality of life and opportunities for participation. It is imperative that housing authorities be seen as critical players in the development and implementation of the Policy Review so that people can realize their right to independent living and community participation. Since the publication of the Policy Review the National Housing Strategy for People with a Disability has been published. This is a welcome development along with the HSE report on Congregated Settings. What is important is that the planning, implementation and monitoring of all three be done in a coordinated manner linking the policy domains of disability and housing.

5.5.7 Over-professionalised - Skill mix

It is true that aspects of disability services have become over-professionalised. However, this direction has been primarily led by government-demanded qualifications and salary-scales. There is an obvious need for much greater flexibility in how people are supported. This will include changes in job descriptions, conditions of employment and skill mix. Member organisations have been changing skill set and mix within organisations for a considerable time. It is also important to remember that other jurisdictions report that the lack of a skilled work force, with low entry level qualifications and salary has created huge challenges of high turnover and poor quality of support. Professor Christine Bigby in 2010 and 2011 urged Ireland not to go the same way and to achieve a balance in this change process.¹² It is critically important that whatever staff are employed that they are competent appropriately trained staff whose focus is on increasing control for the person being supported. The change process will address people who are new to supports, including children and their families, and secondly, people who are currently receiving supports in the more traditional model, some of whom such change may be difficult as older people with disability may no longer have family connections so developing “circles of support” or “community networks” may be more challenging. The challenges for service providers in moving from a current model to providing supports in a more individualised way, is made more complicated by employment law and other factors. There may be a need to maintain a current model for some people while simultaneously moving to a more individualised support model for others.

5.5.8 Technology

We welcome the focus on technology and consider this an important area for further development. The National Federation of Voluntary Bodies held a Sharing Innovative Learning event entitled “[From the Dinosaur Era to the Digital Age](#)” which explored a wide range of technological devices and systems that support an independent individualised life.

¹² IDS Tilda Conference 2010 and 2011



5.6 Commissioning and Resource allocation

Within the section on Commissioning and Resource Allocation the following key issues are addressed:

- Commissioning
- Standards, Quality Measurement, Outcomes and Effectiveness
- Revision of HIQA Standards
- Role of Quality systems
- Person Centred or Programme Centred
- Accountability

5.6.1 Commissioning

The Policy Review places heavy reliance on a market of commissioned services purchased via individualised payments to deliver a range of quality services and supports to the full spectrum of people with Intellectual Disability and Autism. Yet, this is not how we plan and deliver fundamental services like schools or hospitals. There are concerns that a full reliance on a market model may result in fragmentation of services, an emphasis on needs assessment at the expense of interventions, a geographical lottery and inequity in accessing services and supports. Providers may end up spending their time on time consuming tendering processes determined on price rather than on quality. Long term relationships with staff could also suffer under Transfer of Undertaking (Protection of Employment) Regulation (TUPE) and there could be an exit of expertise from the sector. To implement the Policy Review there is a need to have separate funding streams for the commissioning, planning and delivery of services and supports as well as Individualised Funding. The costs of monitoring should be funded additionally and not come out of existing service funding. At the core of the Policy, there is a welcome intent to shift the power to the people and families using services. One of the main ways that this shift in the power balance is to be achieved will be through the allocation of funds to individuals. It is therefore critical that the issue of the Commissioner's role, which is apparently located within the HSE (Page 122) is clarified further. International experience warns that the Commissioner rather than the person or family using supports may become the customer. This will require serious safeguarding in the design of the resource allocation, service planning and commissioning system. International experience would offer salutary cautions that having the infrastructure of funding formulae, commissioning, tendering, regulatory, certification and programmatic provision may not per se lead to the accomplishment of the policy objectives. Instead, there is experience of goal displacement towards a focus on process and protocol with attendant rigidities that frustrate the policy objectives. Rob Grieg advises that "If the Commissioner is not the champion of the Consumer, then they don't know what Commissioning is!" He also advocates for a partnership between the Commissioner and the Provider.

The policy emphasises the goal of people leading a full life. The challenge is to work out what structures and processes will best support this. Being overly doctrinal or rigid will limit the capacity to problem solve. The evidence internationally is that there is a low level of predictability about which structures and processes lead to which outcomes. The proposed solution of fragmenting funding streams, regulatory remits, departmental divisions and programmatic provision risks boxing off administratively convenient pieces of people. There is a constant challenge in supporting people with Intellectual Disabilities to ensure the system focuses on the whole person to prevent them being carved into programmatic pieces. The more paid people there are in a person's life, the more the issue of coordination increases. When this becomes an interagency issue, the

coordination challenge increases exponentially with the risk of people fall through the cracks. The experience of people with Dual Diagnosis is one long running example which illustrates this problem.

The policy refers to ‘Wraparound Services’ as a significant feature of service provision requiring change. However, it is more likely that the real issue is over-supporting people with the consequent dependency and isolation/segregation of people that this can result in, not to mention the poor resource utilisation. However, extrapolating from the notion of a ‘wraparound’ support arrangement to conclude that people should not receive a full range of supports from the same provider seems to go beyond what makes sense. The policy suggests people should be free to act as customers, choosing from an array of providers, but what if the person chooses one provider are their choices being respected? One of the key aspects of the best service provision internationally and in Ireland is the focus on establishing ‘right relationships’. This involves serious consideration and is not a quality that lends itself to administrative neatness or bureaucratic convenience. The facts are what is proposed in the Policy will suit some and not others. The real intent here is to ensure people receive the *least intrusive and ‘just right’ supports* to enable them to participate as citizens and community members. Supports may be formal or informal or both but they need to be tailored to the person not curtailed by the programme boundaries.

It is, however, even more alarming to think that the first step toward the government/HSE’s attempts to approach these funding changes and challenges may be to initiate competitive tendering to existing and new services. Person-centred goals will be totally nullified for an individual whose chosen service fails in the tendering process they will have no continuity of service, no familiar service-location, staff or routines and the successful tendered service may even have no proven track record of service-excellence.

Recent feedback from the UK reported that there appeared to be a level of frustration amongst Commissioners with the UK system with how the Assessment of Need in working across various departments to de bundle money to create specific budgets for people. They faced huge challenges from professionals in terms of working together across departments to support people with disabilities to have real lives. Concern was expressed that some individuals having worked through a computerised resource allocation system resulted in less finances after the process. There is the danger that only critical cases are being funded. This potentially risks individuals focussing on deficits to ensure funding. Furthermore, some assessment of need and resource allocation tools require the need for more and more systems which would be counterproductive to the vision and values espoused in this Policy Review. Regardless any assessment of need process and or resource allocation system will require the need for an approach which involves integrated working, cross agency, cross sector, cross department and multi professional.

In addition it is imperative that we don’t repeat the mistakes of other jurisdictions which end up incentivising “out of county” provision for people who are complex and puzzling. As the report suggests, “service fragmentation impacts disproportionately on people who have multiple complex needs” (p.108). The notion of a person who experiences serious challenges with the service system being supported through the list of separate programme “action areas” (p.59) such as Accommodation, Employment and Training, Health and Wellbeing, Participation is complicated. The Policy needs to actually *reduce rather than increase the impact of stress on individuals and their support systems stemming from systems fragmentation*. We recommend the development of an Assessment of Need (AON), that is strengths and whole life based, is developed from an advanced learning site on Family Centred practice, using Circles of Support and facilitation from outside the service provider organisation which captures the learning from the research, to create an Irish culturally specific Life Plan Support planning process.

5.6.2 Role of Quality systems

It must be acknowledged that there is a tension between standards and quality systems. Most often standards are about minimum standards and not about an overall quality system, usually only focusing on tangible factors such as room size, numbers rather than on the nature of relationships - they also tend to focus on sameness which is a challenge in a more individualised model. Many Irish intellectual disability organisations have invested in different quality systems – however the most common of which is the Council of Quality – Personal Outcomes. This system has been reviewed by a number of jurisdictions and found to have value in supporting organisations to focus on the quality of life of the individuals they support. We suggest that value needs to be discussed in an individualised service model. At a minimum there is a clear need to move well

beyond a standards compliance approach. *Therefore, an essential element which needs to be put in place at the outset is the development of standards for in-home carers and an adequate monitoring mechanism.* The challenge of measuring quality poses some questions about the structural solutions of the policy. The central vision is about people being supported to lead a full life. The structural solutions may actually push a type of demarcation that works against the vision for some or many people. In a sense, there is a 'one size fits all' approach here although unintended. Having individualised funding will not, in itself, lead to there being anything worthwhile to purchase. A programmatic systems architecture can promote or reinforce programmatic mindsets. This is already emerging in the debates among providers about reverting from management models based on the whole person to programme based models. This is being considered so that organisation structures will fit the administrative model of programme level standards for Residential, Day Services etc. This is not promoting the Policy direction and is an example of the unintended consequences that may arise from fragmentation or lack of coherency in the macro system.

5.6.3 Standards, Quality Measurement, Outcomes and Effectiveness

Throughout the policy, the systemic and structural solutions envisage separate departmental and programmatic provision overseen by regulatory or certification bodies with separate standards. This presents a serious challenge to the integrity of the Policy Review vision. The goal of individualisation will constantly be at odds with the requirements for programme level standards. The reference to outcome based standards requires further clarification including who defines the standards, alongside an explanation of the measures of effectiveness on achieving outcomes for people, i.e. whether they are, in fact, being supported to pursue full lives.

Coherency requires that an organising principle or coherent set of values is threaded through the entire fabric of both Policy and Provision. The challenge of developing an option for individualised support while at the same time standardising and regulating existing models pulls in opposite directions. On the one hand, it is intended that people and families will be free to choose and, indeed, direct and design their own personalised support arrangements so they can live as full citizens instead of having to fit into standardised models and structures (p.63). On the other hand the support infrastructure looks likely to be demarcated along programmatic functions which are funded, contracted and regulated as silos. The structural solutions may fragment the vision. Other jurisdictions advise that regulatory oversight using inspection compliance does not substitute for an organisational culture which places those supported at the centre of its activities.

Whatever structures and processes will deliver the policy objectives, it will be essential to build them beginning with the people and families supported and determining what works best in practice from their experience. This will require proper evaluation and learning from evidence and an avoidance of assumptions about what is truly effective. One of the key requirements for determining the effectiveness of new support arrangements will be clarity about the values which in turn inform models and practice. The experience of confusion in the Early Intervention Transformation model has resulted in a proposed Quality Framework that is primarily about having policies in place with comparatively little reference to outcomes for families. It represents an administrative and organisational centred approach that is fundamentally concerned with structures, protocols, policies, etc and the assumption that this will result in family centred outcomes. There is a risk that service providers will revert from management models based on the whole person to programme based models so that organisation structures will fit the administrative model of programme level standards. This is not promoting the policy direction and is an example of the unintended consequences that may arise from fragmentation or lack of coherency in the system.

Throughout the Policy, the systemic and structural solutions envisage separate Action Areas based on departmental and programmatic provision overseen by regulatory or certification bodies with separate standards developed by separate entities with separate inspectorates. The whole process of measurement risks promoting a programme centred model instead of a person centred model. There is a very practical challenge to the integrity of the Policy vision contained here. The goal of individualisation will constantly be at odds with the requirements for programme level standards. The design paradox of standardisation for uniqueness i.e. individualisation, is not addressed. Instead there is reference to outcome based standards. The term Outcome has a different meaning than the term Standard. Who defines the outcomes and how is unclear. If it is the person or family how will their individual perspectives be standardised without being co-opted into and conflated with organisational and sectoral definitions. This would really need to be addressed.

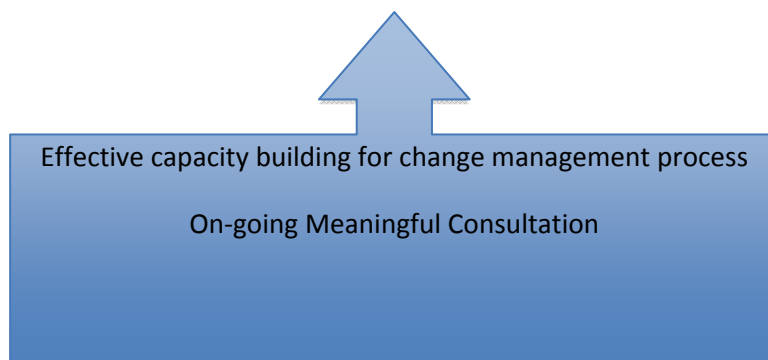
The measures of effectiveness will presumably be based on the notion of outcomes for people, i.e. whether they are in fact being supported to pursue full lives. It is therefore critical that what is meant here by outcome based standards be fully fleshed out and described. Otherwise, there will be no way to determine the progress that is being made.

5.6.4 Revision of HIQA Standards

An additional point of note is that the HIQA Standards will require a significant redesign. They currently assume housing and provision are delivered via a single provider. As this changes there will be a need to ensure the Standards for Housing and for Support are working from the same values and principles. The development of more individualised arrangements will also require a different design for quality assurance. This will, in turn, challenge the programmatic design of standards into residential, day, etc domains.

5.6.5 Accountability

On a general point, the deconstruction of provision will make it difficult to determine accountability for the person's full life outcomes. Each separate entity of provision will have distinct regulatory frameworks which are designed as programme level standards such as housing, employment, supported living and meaningful day opportunities. It is imperative that the problem of a high level of dependence on single providers providing poorly tailored supports is not simply replaced with a series of fragmented silos that will require such a focus on interagency interdepartmental protocols and administrative gantries that will require significant energy and attention going into the administrative and bureaucratic crevasses. This is a recipe for administrative centred approaches and poor resource utilisation. The issue of whole life outcomes and how these are facilitated through a series of separate programmes needs much more consideration. It cannot be stated enough - *people's outcomes are very often multifaceted and do not fall neatly within programmatic boundaries*. Any assumption of neat fit will be a real challenge for the Policy and afterthought solutions are generally expensive and ineffective.



5.7 Effective Capacity Building for Change Management Process

Within the section on capacity building the following key issues are addressed:

- **Innovation**
- **Implementation Challenges**
- **Separation**
- **Impact Assessment for reallocation of MDT Staff during Implementation**
- **Leadership, Learning and Capacity Building**
- **Measuring Progress**

5.7.1 Innovation

International experience with elaborate infrastructures for assessment, resource allocation, commissioning, tendering, certification, etc would at least pose significant cautions about how well the system accommodates innovation. It appears to be a universal experience across jurisdictions often cited in the policy e.g., Canada, New Zealand, Australia, that innovations must go “under the radar” as they don’t fit the particular administrative requirements of funders or they, in some way, deviate from the contracts tendered for and all the legal ramifications of this. The policy vision will require innovation if the radical and positive changes for people with disabilities are to be realised. Throughout this review of the policy proposal, the challenge of achieving a balance between individual empowerment and fragmentation of support systems has been the recurring theme. The dilemma is that for some or perhaps many people, the fragmentation of supports may undermine empowerment in a system that may be complex and opaque and at times seeming at odds with its own vision.

5.7.2 Implementation challenges

This is a policy document and not an implementation plan and as such it needs to set out a vision approaching an ideal. In setting out such a vision we also need to be cognisant of the potential issues around implementation. There is no doubt there will be challenges to the reconfiguration of existing services. For individuals and families there will be fear of the unknown and uncertainty. For many people with disabilities they have spent a life time in a dependent service culture with limited choice and opportunity and now are being exposed to option and possibility of choice. This will be daunting for some. However, the capacity of individuals and families must not be underestimated. It will be critical that attention and focus is paid to the strengthening and capacity building of individuals and families throughout this change process. For individuals and families receiving services in more traditional settings a well thought out transition plan will be necessary to guide this process with on-going challenges of funding, staff resources etc.

For staff the challenge will be the new way of working, change in roles and job descriptions possibly redeployment. Staff will be required to be facilitator, enablers, community connectors rather than carers. There will be a need for a more flexible approach to working and the challenge to their values and beliefs held regarding people with disabilities. Notwithstanding the challenges, the outcome will be more fulfilled lives for people with disabilities and their families, greater job satisfaction for staff and employees and a more inclusive society. A strong, well thought implementation plan will be critical to the success of the policy. We recommend that this incorporates accelerated learning sites as highlighted in the report, “Time to Move on from Congregated Settings: A Strategy for Community Inclusion”, (2011) for sharing good practice and piloting initiatives to measure success before national implementation. While the policy is strong on setting the vision and values and a promise of a better future for people with disabilities the implementation plan must be

strong on the 'how to'. In the case of building communities, vision building is required at a community level. Service staff with a background of volunteering and capacity building can complement local efforts. A more integrated understanding of what work is done, what needs to be done and how it can be progressed may help policy effect greater change. Much expertise and experience has been built up in organisations over many decades. This skill base is essential to the implementation of the Policy Review. Retention and refocusing key staff is therefore critical. Change should be introduced purposefully and thoughtfully, with sensible timeframes, be genuinely person centred and genuinely improve people's quality of life, not be simply driven by ideology or cost savings. Quality of life outcome measures should be developed at the outset of the implementation of the policy to ensure changes are actually improving the lives of people with intellectual disability and autism, as well as the parents and families that support them.

Managing the transition from block-funded services to individualized supports is a complex task. The approach to restructuring the sector needs to be discerning. It should not dismantle demonstrably effective arrangements which, in fact, represent current best efforts to enact the thrust of the Policy vision of empowerment and inclusion. *Dismantling such arrangements without having a stronger, proven alternative would make no sense* and would cause a lot of anxiety and dislocation. In the same vein it is important that the sector is encouraged to pursue innovative support arrangements. There is a danger that existing or new organisations will focus on preparing programme domains for achieving certification against the relevant standards in an effort to reconfigure provision to fit the administrative map. Programme domains do not represent models of individualised and person centred support. However the effect of the Policy may be to incentivise provider efforts to position themselves in conformity with certification requirements. In an environment where there are competing priorities individual arrangements could receive less attention, particularly as they are more challenging and administratively untidy compared to the programme level services. It is therefore critical that the innovations that represent the best efforts nationally to implement the Policy vision remain incentivised. It is notable that the Policy makes little reference to existing examples of innovation and it is not clear how the knowledge and experience gained, largely by providers in the voluntary sector, will be engaged with. Furthermore unless innovation continues to be actively encouraged this knowledge may be lost as organisations focus on other imperatives. The Policy Review espouses a social model approach, but requires a deeper exploration of this, on understanding the barriers to participation.

5.7.3 Separation Health and Personal Social Services

Structures can support or impede implementation and the question of where in Government disability supports should lie has to be addressed. We warmly welcome the debate on the location of disability support funding within the Government Structures and the separation to health and personal social services. We would welcome participation in this debate, exploring the appropriate Departments for Children & Families and Adults. Since 2009 in the UK funding for social supports under the Valuing People programme is delivered through local authorities and community care while health-related support is delivered via the National Health Service. The Department of Social Protection currently provides income support to many people with disability, and the possibility of using this department of government as a vehicle for the delivery of social support funding should be actively explored. As long as funding for both health and social support derive from the same source it will remain difficult to isolate which parts of the funding are dedicated to social supports and which to health or health-related support. It also means that in a climate of limited resources within the health services there will be competition between medical services and social services for available funds. This is because while the whole population has a need for medical services at some point in their lives, not everyone will require the types of social support which are essential for people with disabilities to live independent lives. Where there is competition for limited resources social services are likely to be the comparatively more vulnerable to budgetary cutbacks. Although the Alma Mata Agreement's definition of health is about health and social gain, the reality is that health is interpreted as medical. However, it is essential to ensure that the current funding for personal social services from the health vote will transfer and follow people to the new Department.

Policy Goal 2 notes that the overall HSE governance structure is still 'under construction' – and it will be vital for the Policy Review Group to make recommendations in this respect. Since the HSE will be carrying out the objectives of any new policy framework for disability supports at ground level, it will be critical to ensure clear lines of responsibility and reporting, as well as a consistent approach at national level (to needs assessment,

early intervention teams, etc.). If personal social services move out of health how will this impact on the relationship with the HSE?

5.7.4 Impact Assessment for reallocation of MDT Staff during Implementation

There is an important point concerning the need for an impact assessment on the stripping out of some Multi-Disciplinary teams (MDT) and the cost benefit arising locally. For example, in some agencies, MDT staff may be involved in managing supports for vulnerable people in relatively low cost arrangements. The impact of simply stripping these out may result in major gaps of support and subsequent breakdown of individual situations with a resultant high cost. The reality of this may vary considerably from agency to agency but it does not need to be assumed one way or the other. The principle of impact assessment should also be used in ensuring that what is being changed is understood in terms of its ramifications so that the process does not lose credibility.

5.7.5 Long-term Future Funding

We propose the need to look more creatively at the long term future funding of disability supports and to explore models in other jurisdictions such as taxation incentives saving plans for people with disabilities and their families to plan for their futures. See the Centre for Disability Law & Policy (CDLP) proposal entitled Avoiding the poverty trap and achieving economic empowerment for persons with disabilities: *An Analysis of the United States Legislative Initiative 'Achieving a Better Life Experience' ("ABLE") Bill of 2009* which can be found at the link below.¹³

5.7.6 Leadership, Learning and Capacity Building

While leadership is not addressed in the Policy Review it will be imperative to ensure that there is a focus on fostering leadership at every level across different stakeholder groups based on a shared vision and common values. We suggest that the capacity building process used by the National Development Team and Valuing People in the UK offers a really worthwhile model that should be looked at as an example of how the leadership and know how at every level was supported for people and families, providers, policy makers etc.,

¹³ See http://www.nuigalway.ie/cdlp/documents/publications/policy_briefings/Policy%20Briefing%20No%203.pdf last accessed the 18.11.11

6.0 Conclusions and Recommendations

The Policy Review is necessary and timely giving an overarching vision and direction for the future. The vision is appropriately ambitious and is particularly welcome in these fiscally fraught times as a sign of leadership and determination to go forward. We consider that consultation and participation are essential elements of policy development. We are concerned at the absence of a comprehensive system of consultation and participation in the drafting of this document and are concerned at the implications of lack of consultation and participation for the change management and implementation process. We make the following recommendations:

1. We propose to amend the Vision Statement to read: *To realise a society where people with disabilities are supported to participate fully in economic and social life **as equal citizens of this country** and have access to a range of quality supports and services to enhance their quality of life and well-being.*
2. We propose that the Key pillars towards citizenship are:
 - Voice of people with intellectual disability –a strong focus on advocacy leading to a national platform,
 - Self-determination for people with intellectual disability and an individual life plan
 - Strong and effective Family Leadership
 - Community inclusion and real participation
 - Mainstream provision skilled up and accessible
 - Individualised services and supports towards real lives with the option of support through brokerage and hub systems
 - Cross department responsibility for people with disabilities within a social model /human rights framework/ utilising the UNCRPD
3. In the implementation of the Policy Review we propose an **Appreciative Inquiry** approach that looks at what is working in the existing systems, especially the innovative and person centred aspects and what aspects need to change to create and understanding of how best to create the change required.
4. There is a need to outline a process of more **extensive engagement with people with intellectual disability and autism and families** to ensure support for the Policy Review Vision. This will require the preparation of an easy to read version of the Policy Review and a facilitated consultation process to access all people with intellectual disability and autism.
5. We recommend that **Family Leadership** needs to be urgently addressed and developed within the Policy Review. We suggest that support for family leadership initiatives should be discussed as part of the wider advocacy strategy. We suggest that there needs to be substantial investment to support building the capacities of people with an intellectual disability and their families to shape and develop the services and supports they need.
6. We recommend the expansion of **Self and Peer Advocacy** within the Policy Review as an essential part of its implementation in supporting the self-determination of people with intellectual disabilities at a personal level and as a Network with whom the Department of Health and Children (DOHC) and others could consult. It is important that the voices of people with disabilities be included not just at the level of individual services, but also at the policy making level. We support the establishment of a **National and Regional Platform of Advocates**.
7. We are concerned that the overall focus of the Policy Review is much more developed for adults and that a similar depth of research has not been undertaken in relation to **children**. We propose the future policy direction as it applies to **children** receives a more in depth analysis.
8. We strongly suggest that a **distinction** be made between families with young children from birth through **pre-school and early school years** and children who are of established **school age**, young adolescents or approaching adulthood. We propose that Family Centred practice is the foundation for person centred practice in adulthood.

9. It is the view of the National Federation of Voluntary Bodies that there is an insufficient commitment to **Family Centred practice** within the Policy Review. We recommend that a **Family Centred approach is embraced as a core element of the Policy Review**.
10. We propose that the **definition of disability** in the Disability Act 2005 needs revision to focus on person's strength and abilities and the environmental barriers to participation.
11. We recommend the development of an **Assessment of Need (AON), that is strengths and whole life based**. It should be developed from an advanced learning site on Family Centred practice, and one on Visionary Person Centred Planning, using Circles of Support and facilitation from outside the service provider organisation which captures the learning from the research and Person Centred Planning to create an Irish culturally specific **Life Plan Support** planning process.
12. There is concern that the commitment to Mainstream Education is not strong enough within the Policy Review. The future role of special schools in the context of a mainstreaming policy needs to be examined further.
13. We recommend that **older people** be more clearly included in the Policy Review addressing the need to plan for the ageing population of people with disabilities. We support an "aging in place" policy.
14. We propose that it is critical for the Policy Review to consider the **risk of fragmentation** to "**the Person's story**" and identify safeguards that can be put in place to prevent this. We propose that "Who holds the Person story?" becomes an active research process in an advanced learning site to address: (a) the process of the person centred vision being developed outside the service provider organisation and how to keep the plan "live" and (b) how fragmentation can be avoided by effective coordination to "hold the person's story" and to ensure an accountable process to reach agreed outcomes is achieved which can have universal application.
15. We recommend that the Implementation Process of the Policy Review incorporates **accelerated learning sites** as highlighted in the report, "Time to Move on from Congregated Settings: A Strategy for Community Inclusion", (2011) for sharing good practice and piloting initiatives to measure success before national implementation.
16. We consider the brief but pertinent discussion in the Policy Review on **Duty of Care** in relation to individualised supports is very important and needs to be explored further to secure legal agreement.
17. We suggest that the **leadership and capacity building process** used by the National Development Team and Valuing People in the UK offers a worthwhile model that should be looked at as an example to support people, families, providers, and policy makers.
18. We propose the inclusion of the **Informing Families Guidelines** in the Policy Review and seek their **national roll out**.
19. We propose that the Policy Review needs to be much clearer about the difference between individualised **Outcomes and Standards**.
20. We suggest that the significant **coherency issues** are addressed within the Policy Review including how will whole life personalised support arrangements grow out of standardised programmes?
21. We suggest reviewing the funding and commissioning system in the Policy Review to ensure that it is **responsive and incentivises innovation**.
22. We recommend that the Policy Review acknowledges the diversity of people with disabilities and especially those with more significant support needs and that it is critical that the Policy Review Implementation Plan addresses the prioritising of people with high or complex support needs.
23. We advocate for a strong vibrant responsive not for profit service provider sector working in collaboration and partnership with the key stakeholders.