Centre for Disability Law and Policy NUI Galway

Submission on the Future of Disability Policy in Ireland

Centre for Disability Law and Policy, NUI Galway

The Centre welcomes the opportunity to make this submission on the future of disability policy in Ireland. The Centre for Disability Law and Policy (CDLP) at the National University of Ireland Galway was formally established in 2008. The Centre's work is dedicated to producing research that informs national and international disability law reform. Since its establishment, the CDLP has organised a number of key events to provide a space to discuss disability reform, such events include: an International PhD Colloquium (2010), an international conference on national disability strategies (2010), a Summer School in conjunction with the Harvard Project on Disability (2011) and a national conference 'Active Citizenship and Disability' examining the transition to individualisation of services and supports (2011). The Centre regularly runs seminars and public lectures and produces policy briefings. The CDLP runs a Ph.D programme and a Masters (LL.M) in International and Comparative Disability Law and Policy.

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Executive Summary

The Centre for Disability Law and Policy welcomes the publication of the Report of Disability Policy Review by the Expert Reference Group on Disability Policy, and the opportunity to contribute to the formulation of a new framework for delivery of supports to people with disabilities in Ireland. The policy represents a major breakthrough for people with disabilities and holds the potential to provide a sound basis from which people can claim real citizenship.

Although Ireland has not yet ratified the UN Convention on the Rights of Persons with Disabilities, it is important to acknowledge the significance of Ireland's position as a signatory to the Convention. This submission will aim to set out clearly the existing and forthcoming obligations on Ireland with respect to the rights of people with disabilities, which should be reflected in a process of disability policy reform.

This submission will also seek to emphasise the importance of joined-up thinking between this policy and other current legislative and policy initiatives in order to ensure that full, effective citizenship is guaranteed to people with disabilities.

The success of the policy will depend on other key developments which are essential to enabling people realize their full human rights. In particular it is imperative that a comprehensive framework which recognizes people's legal capacity and which provides a continuum of supported decision-making structures is put in place. The current absence of such legislation and structures represents a major barrier to the ability of people to exercise choice and control in their lives.

Secondly, the publication of the National Housing Strategy for People with a Disability and the report of the HSE Congregated Settings working group are highly significant, especially when considered in conjunction with the new disability policy. Both documents have broadly the same aims of independence and inclusion for people with disabilities as the new disability policy. And while the Congregated Settings report focuses on the closure of institutions, both address what can be considered a major housing (or re-housing) programme for disabled people. Like all citizens, people with disabilities require housing, and all three documents foresee them accessing the same range of housing options as the rest of the population. The additional element for disabled people is the support they may require to access or remain living in their own homes. It is imperative that the relevant government departments work closely together in developing and implementing the housing and support aspects of this process.

The policy places paramount importance on individual choice and control and this is welcomed wholeheartedly. However, at the same time it proposes that no more than four people with disability be accommodated together. This seems to be at odds with the overall thrust of the policy and holds the danger that practices common in institutional settings will be replicated in such smaller units. Institutions are defined not merely by their size but also by practices

which regulate individual's routines in accordance with the needs of the group. For this reason we recommend that the stipulation of a maximum number of people living together be dropped from the policy.

The importance of genuine partnership working among all stakeholders is identified as crucial in the realization of the aims of this policy. Perhaps the two most important stakeholders are people with disabilities themselves and their families/advocates who can act as powerful forces for system change. It is important that in developing new policies and practices that the voice of people with disabilities and their families are listened to. To this end there is a need to support the development of self-advocacy groups, other forms of advocacy and the development of family networks and family leadership in the change process.

The policy aims to ensure that people remain connected to their families and be fully included in their communities. Such networks of support are one of the most important means of ensuring people's safety and well-being. The policy will also facilitate people living in their own homes and enjoying the same benefits of home as their fellow citizens. However, it is important that the State take responsibility for the quality of supports available to people at home, and in this regard it is important that standards for in-home support providers be developed and implemented in a manner that respects people's dignity, rights and privacy.

It is important to recognize that many people with disabilities will require on-going formal or specialized supports, especially people with higher levels of need. The policy must ensure that the natural supports provided by families are not seen as a replacement for these formal supports. This is crucial, both in supporting people with disabilities, but also in supporting families and enabling them to cope well with all of the ordinary pressures of life as well as those arising from caring for a disabled son or daughter.

The mainstreaming of services for children with disabilities is a process which is already underway, and the policy stresses the importance of enabling families to care for their child at home. Critical to this will be embedding a family-centered philosophy in the inter-agency and cross-discipline teams working with children and their families. This way of working will emphasise family strengths and capacities, will empower families and will enable professionals to work in partnership with families.

Currently health-related and social supports for people with disabilities are funded and delivered through the health system and it is not proposed to change this in the new policy. Most people with disabilities are not ill, but many require social supports to get on with their lives. As long as the two types of support are channeled through the health system it will remain unnecessarily difficult to achieve the fundamental principles of the social model of disability which are expressed in the policy proposal. For this reason we suggest that funding for social supports be moved out of the Department of Health and channeled through the Department of Social Protection.

Introduction

The Centre for Disability Law and Policy welcomes the publication of the Report of Disability Policy Review by the Expert Reference Group on Disability Policy, and the opportunity to contribute to the formulation of a new framework for delivery of supports to people with disabilities in Ireland. At this point we need to move away from the language of services and needs and towards a new conception of supports which will enable people to have a life and will create the conditions for their flourishing in the community. The policy is a significant step along this road for disable people and for the community as a whole.

This policy review is part of a broader framework of reform which is currently underway in Ireland. This includes the enactment of capacity legislation, the establishment of the National Advocacy Service, the publication of the Congregated Settings report and the Housing Strategy for People with a Disability, and ultimately, Ireland's ratification of the Convention on the Rights of Persons with Disabilities (CRPD). Our submission will seek to emphasise the importance of joined-up thinking between all of these initiatives to ensure that full, effective citizenship is guaranteed to people with disabilities.

Although Ireland has not yet ratified the UN Convention on the Rights of Persons with Disabilities, it is important to acknowledge the significance of Ireland's position as a signatory to the Convention – which implies a willingness to uphold the principles of the Convention, and not to take steps which would be contrary to the spirit and purpose of the Convention. In addition, the CRPD merely restates existing international human rights law as it applies to people with disabilities and does not contain new obligations as such. This submission will aim to set out clearly the existing and forthcoming obligations on Ireland with respect to the rights of people with disabilities, which should be reflected in a process of disability policy reform.

Legal Capacity

Article 12 of the CRPD clearly identifies the right of people with disabilities to '*recognition everywhere as persons before the law*.' This includes the right to '*enjoy legal capacity on an equal basis with others in all aspects of life*.' It entails not only the right to be a holder of rights before the law, but also the right to be an actor underneath the law.[1] This right is particularly important in the context of housing and independent living policies related to people with disabilities. The recognition of an individual's right to legal capacity is the recognition of his or her right to make decisions regarding where and with whom to live. In this way, the right to independent living and community inclusion (CRPD Article 19) and Article 12 are intricately entwined and should be recognized in the new disability policy. Quinn, Bach and Kerzner have argued that the rights relating to legal capacity cannot be fully realised without ensuring that people can live independently and be included in their community. This includes having genuine choice and control over the services and supports they require.[2]

The introduction of individualised services and funding is an important development, and one which must be combined with legal frameworks to enable people to exercise choice and make decisions which are legally recognised, using the appropriate supports. Unless there is clarity in the legal framework regarding decision-making, people will not be able to exercise choice and control over the services and supports they wish to purchase. It is vital to ensure that a supported decision-making framework is in place, which will enable individuals and families to navigate the process of choosing services and supports, and making financial, legal and healthcare decisions which can have full legal effect.

To this end, we propose that any system of individualised funding is accompanied by robust legal capacity legislation, which recognises the validity of supported decision-making in all aspects of life[3] – including decisions about services and supports. 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).[4] The success of individualised funding is

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[1] "Legal Capacity," *Background conference document prepared by the Office of the United Nations High Commissioner for Human Rights,* available at
http://www2.ohchr.org/SPdocs/CRPD/DGD21102009/WNUSP_Legal_Capacity.doc
[2] See Quinn "Rethinking Personhood: New Directions in Legal Capacity Law & Policy" (Vancouver: University of British Columbia, 29 April 2011) and Michael Bach and Lana Kerzner, "A New Paradigm for Protecting Autonomy and the Right to Legal Capacity," prepared for the Law Commission of Ontario (October 2010), at 7-8, available at www.lco-cdo.org/disabilities/bach-kerzner.pdf (last accessed 18 October 2011).
[3] Centre for Disability Law and Policy, *Submission on Legal Capacity to Oireachtas Committee on Justice, Defence and Equality* (2011).
[4] See Representation Agreement Act (RSBC 1996 Chapter 405). A Representation Agreement is a legal document available to all adults in British Columbia for personal planning. It enables individuals to appoint one or more personal supporters as representatives to help manage their affairs and, if necessary, to make decisions on your behalf in case of illness, injury, or disability, and is generally regarded as a positive, empowering alternative to adult guardianship.

intrinsically linked to the exercise of legal capacity. To ignore this link could lead to a situation where people with disabilities and their families have to navigate complex legal issues concerning employer's obligations, quality control and financial management, without the right supports to guide them through this process. Such an approach would be in conformity with the UN CRPD.

Recommendation

The individualisation of funding should be accompanied by robust legal capacity legislation, which recognises the validity of supported decision-making in all aspects of life. 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.

Individualisation

Article 3 of the CRPD details the core principles underlying the convention. These include respect for the dignity and autonomy of the individual, full participation in society, accessibility and equality of opportunity. The individualization of services and supports is the only way in which these principles can be realized and it is a very welcome development in Irish disability policy. The individualization of funding is key to the realization of Article 19 and its protection of the right to live independently and to be included in the community. Article 19 must be carefully incorporated into any policy related to individualization of funding and services.

The policy proposal aims to ensure that people can live in ordinary, fully integrated independent settings in their local community. It also recognizes the importance of where one lives to the level of community participation that is possible. However, in common with the report of the HSE Congregated Settings group, it recommends that funding should be directed to residential settings accommodating no more than more four people with disability. This recommendation seems to be at odds with the overall thrust of the policy. By placing a figure on the number of people who may be accommodated together there is a danger that this becomes the benchmark. In effect it could legitimize four person group homes in communities.

Institutions are not solely defined by size and it is quite possible to transfer institutional living to smaller community-based houses. The European Coalition for Community Living defines an institution as '... *any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.'* [5]

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. As noted by Mansell et al '... *replacement of institutions by community-based alternatives provides opportunities but does not, in itself, guarantee better outcomes – it is a necessary but not sufficient condition.'*[6] There is a danger that by mandating four person residential units that many of the features of institutions could be replicated there - such as regulated meal times, bed times, bath times etc - and that individual choice could be overshadowed by the needs of the group.

We suggest that the emphasis of the policy on the individual's right to choice and participation be maintained throughout and avoid any stipulation with regard to numbers of people who can be accommodated together.

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[5] European Coalition for Community Living www.community-living.info/?page=280 Accessed on 3/11/2011

[6] Mansell, J. Beadle-Brown, Clegg, S. *Included in Society: Results and recommendations of the European research initiative on community-based residential alternatives for disabled people.* Brussels: Inclusion Europe, 2004 P56

There is ample historic evidence of the vulnerability of disabled people to exploitation, neglect and abuse in institutional or congregated settings. However, there are some predictable vulnerabilities for people living in individualized arrangements which we also need to be cognizant of. In particular the vulnerability of individuals in receipt of direct payments to cutbacks both in the payments themselves and in the funding of related supports. Where people are individually funded changes in the level of payments or in the funding systems can have major impacts, which people individually may have little power to oppose. This was highlighted this year when Birmingham City Council[7],in seeking to make major budgetary cutbacks, proposed to remove funding from people with 'substantial' needs and develop more universal access to mainstream services as a compensatory measure. Four individuals with significant disabilities with the support of their families successfully challenged the Council decision in the High Court. However, for many people with significant disability, access to the courts is an insurmountable obstacle and it is untenable to depend on the willingness or ability of individual citizens with disability to challenge the impact of cutbacks or re-structuring in the courts. The policy proposal could consider how to safeguard people's income and supports in the context of the need for overall government cutbacks, given the particular difficulties people with disabilities encounter in accessing justice and the historic marginalization they have experienced.

The emphasis in the policy on opening up access to all types of secure housing tenancy and ownership routes to people with disabilities is to be welcomed. As noted in the proposed policy it is internationally accepted good practice that people's housing and support should be provided by separate agencies in order to ensure that problems encountered with either one does not jeopardize the other. However, it is important to note that several of the current disability service providers have established housing associations in order to access social housing for people with disabilities. These housing associations are in effect sister organizations of disability service providers, although they are legally separate agencies. The personal support in these housing associations is usually provided by staff members of the disability service provider. This is route to social housing which has been supported by the Department of Environment and it has proved to be an important source of good quality housing for many people with disability – in 2007 a survey conducted by the Irish Council for Social Housing noted that 1149 people with intellectual disability and 504 people physical disability were being accommodated by housing associations.[8] The policy proposal recommends that disability service providers no longer operate housing associations. In contrast, the recent National Housing Strategy for People with a Disability appears to support this method of housing provision. In this context it is suggested that the recommendation that disability service providers cease to operate housing associations be re-considered. The broadening of the membership of the boards of housing associations to include

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[7] Birmingham City Council v W and Birmingham City Council v M, G and H. 2011 Case Numbers CO/1765/2001 and CO/1772/2011
[8] Irish Council for Social Housing *Enhancing Choices for People with Disabilities in the Community: Survey Findings on Social Housing Provision for People with Disabilities in the Voluntary Housing Sector.* (2007)

representatives from other sectors of the community is one option which could usefully be considered as an alternative.

Recommendations

The emphasis of the policy on the individual's right to choice and participation should be maintained throughout and should avoid any stipulation with regard to numbers of people who can be accommodated together.

Where people are availing of individualized funding, consideration should be given to how to safeguard people's income and supports in the context of overall government cutbacks, given the particular difficulties people with disabilities encounter in pursuing their rights through the courts.

The recommendation that disability service providers no longer establish or run housing associations should be re-considered. Instead consideration should be given to the option of encouraging housing associations currently operated by disability service providers to broaden their board membership.

Assessment of Need and Planning

In order to ensure that the commitment in Article 19 of the CRPD that *'community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs'*, individualized assessments of the support needs of people with disabilities must be undertaken. However any needs assessment system must be one part of creating the conditions, and putting in place the supports, which enable people to flourish in the community. We need to move away from the language of services and needs and focus on envisaging how the State can ensure that people can live their lives as equal participating citizens. The proposal in the new policy to put in place an independent needs assessment process which is person-centered and covers all areas of the individual's life is to be welcomed.

The policy recognizes that the current needs assessment process for young children under the Disability Act 2005 is inappropriate and is in conflict with the new proposals. Under section 4 of the Education for Persons with Special Educational Needs Act 2004 all children with disabilities are entitled to an assessment of need to be conducted by either the HSE (health boards at the time of enactment) or the National Council for Special Education.

One of the findings of the Commission on the Status of People with Disabilities was the frustration which disabled people and their families experience because of the multiplicity of agencies involved in undertaking assessments.[9] The commission recommended that there *'…should be a new Assessment of Needs process, underpinned by law, with adequate arrangements made for its enforcement and monitoring and for an appeals procedure, and it should lead to a Statement of Needs'*[10] and that assessments should be carried out by agencies accredited by the State.

The new needs assessment process must be cognizant of this frustration and of the need to avoid any unnecessary intrusion into the person's life or duplication of processes.

For this reasons we recommend that the new needs assessment be fully comprehensive of all domains of a person's life, including the education domain. Consideration should be given to incorporating educational needs assessment under the EPSEN Act with the supports needs assessment process outlined in the policy proposal.

The linking of the outcome of the assessment process to individual support plans is welcome. It is important, however, that the support planning function is identified as distinct from the day-to-day coordination and development in

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[9] *A Strategy for Equality, Report of the Commission on the Status of People with Disabilities,* Government Publications 1996, Section 4.1 Accessed at www.nda.ie/cntmgmtnew.nsf/0/9007E317368ADA638025718D00372224/$File/strategy_for_equality _06.htm

[10] *A Strategy for Equality, Report of the Commission on the Status of People with Disabilities,* Government Publications 1996, Section 4.34 Accessed at www.nda.ie/cntmgmtnew.nsf/0/9007E317368ADA638025718D00372224/$File/strategy_for_equality _06.htm

managing a person's supports. Support planning arising form the needs assessment process, should provide '... *a mechanism which discovers what are the wishes and preferences of the individual and what kind of supports would be useful in enabling that person to achieve these.'[11]* This function, which could also be termed 'life planning', is essential in ensuring that the allocated individual funding is used in a manner which assists the person in achieving his/her long and short term goals, and includes a mechanism for regular review of how well this is being realized in the light of the person's changing needs and wishes.

> **Recommendation:**
>
> **The needs assessment process should be fully comprehensive of all domains of a person's life, including the education. Consideration should be given to incorporating educational needs assessment under the EPSEN Act with the supports needs assessment process outlined in the policy proposal.**
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> **Support or life planning, focused on people's goals and wishes, should be separate from the day-to-day management of people's supports.**

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[11] Power, A. *Active Citizenship and Disability: Learning lessons in transforming supports for persons with disabilities* Centre for Disability Law and Policy NUI Galway (2011) P8

Mainstreaming

The preamble of the CRPD emphasizes *'the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development.'* This highlights the need for mainstreaming at the core of the new disability policy. The new proposal has a welcome emphasis on the mainstreaming of services and supports for disabled people. The benefits of mainstreaming for all citizens are well recognized. However, it is important to ensure that the definition of mainstreaming encompasses:

A) The provision of supports to enable people to access generic services and facilities

B) The provision of reasonable accommodation by mainstream providers to ensure full access and participation

C) Design, modifications or adaptations of mainstream services and facilities themselves so as to enable access for disabled people.

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 or too far-fetched.

At the same time it is important to recognize that many people with disability will require long-term specialized services and supports, especially people with severe or profound disabilities. The Commission on the Status of People with Disabilities highlighted the particular vulnerability of this group of people stating that *'…they will inevitably be dependent on significant state support throughout their lives, irrespective of the resources of their families. Thus, the state has a special responsibility to act as guarantor of their health services, safety, and quality of life. Their vulnerability and dependency require special measures to protect their interests and maximise any possibilities that they may have for exercising personal choices.'[12]*

There is a danger that the laudable emphasis on the attainment of independence and mainstreaming will overlook the fact there will always be a requirement for targeted specialist services for a significant percentage of disable people. One of the major dangers with a universalist approach in any sphere is that, in seeking to address the needs of all, that it will fail to address the particular needs of some. This is recognized by Bickenbach et al when they note that *'To insist on universalism in a disablement classification* [the WHO Revised International Classification of Impairments, Disabilities and Handicaps – ICIDH -2] *is not, however, to suggest that the personal and social burdens of disablement are unevenly distributed, or to undermine political attempts to draw attention to this*

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[12] *A Strategy for Equality, Report of the Commission on the Status of People with Disabilities,* Government Publications 1996, Section 23.2Accessed at www.nda.ie/cntmgmtnew.nsf/0/9007E317368ADA638025718D00372224/$File/strategy_for_equality_06.htm

inequality.'[13] It is clear that there is an need for both – a universalizing or mainstreaming of disability policy and a targeted approach which deals with the specific or 'special' needs of some who cannot be fully accommodated by universal/mainstream provision – inevitably those with more severe or unusual impairments.

> **Recommendation:**
>
> **The definition of mainstreaming should encompass the provision of supports to enable people to access generic services and facilities, the provision of reasonable accommodation by mainstream providers to ensure full access and participation and the design, modifications or adaptations of mainstream services and facilities themselves.**
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> **The emphasis on mainstreaming and independence should not overshadow the situation of people who are highly dependent and will require long-term specialist supports.**

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[13] Bichenbach, J.E., Chatterji, S., Badley, E.M. & Ustun, T.B. *Models of Disablement, Universalism ad the International Classification of Impairments, Disabilities and Handicaps* in Social Science and Medicine, 1999, Vol 48 P1185

Standards and safeguarding

Article 16 of the CRPD asserts the right of people with disabilities to be free from exploitation and abuse. It obliges States to '... *ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.'* This right is important in the context of individualization because it clearly establishes the responsibility of government to put in place safeguards and monitor individualized housing and support arrangements.

The proposed policy aims to ensure full inclusion and self-determination for people with disability. Integral to this will be enabling disabled people to choose where and with whom to live and having the supports needed to make this to happen. It will mean that people will no longer be obliged to live in any particular living arrangement because of their support needs, as is currently the case for many people with disability in Ireland.

It is widely acknowledged that the best safeguards for vulnerable people are being known in, and connected to, community, and the assumption of power and control by people in their lives. As highlighted in the UK '*Strengthening citizenship and communities in line with the personalisation agenda can contribute to keeping people safer. Self-directed support enables people to have choice and control over their lives, and be active citizens rather than passive recipients of services. People who have choice and control over their support arrangements, keep in touch with family and friends, and stay active and healthy, are likely to be at less risk of abuse than those who are isolated and dependent on services.'[14]* It is clear that the new policy aims to achieve this for disabled people in Ireland. The evaluation of Individual Budgets Pilot Porgramme in the UK concluded that, although there was widespread concern among families and service staff about increased vulnerability, there was little evidence to support this in practice. Nonetheless the need to ensure that effective monitoring and review of individualized services is in place was identified. This helped to increase the confidence of individual budget holders and staff and encourage greater creativity .[15] It is imperative that people can trust that support provided to them in their own homes will be of consistently high quality and will be flexible and responsive to their needs as directed by themselves or family/advocates as appropriate.

The CDPL welcomes the recognition of the need for quality standards in the new policy proposal. At present in Ireland there are no national standards regulating in-home care/support providers for disabled or elderly people. In such an unregulated environment people are vulnerable to mistreatment, exploitation and abuse. In addition where mistreatment occurs in ones own home it can be more difficult to identify and rectify, especially if the person is less able to

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[14] Practical Approaches to Safeguarding and Personalisation, Dept of Health, UK 2011 P7 accessed at
www.thinklocalactpersonal.org.uk/_library/PPF/NCAS/Practical_approaches_to_safeguarding_and_personalisation_12th_Nov_2010_v3_ACC.pdf
[15] Glendinning, C. et al. Evaluation of the Individual Budgets Pilot Porgramme: Final Report Social Policy Research Unit, University of York, UK. 2008 p249 Accessed at
www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf

communicate or to make a complaint. Therefore, an essential element, which needs to be put in place at the outset, is the development of standards for in-home carers/support providers and an adequate monitoring mechanism. Such standards must include robust and fully accessible complaints procedures, which are independently administered and investigated.

The Law Reform Commissions paper *Legal Aspects of Carers* published in 2009 made several provisional recommendations concerning this issue. In particular the report recommends that the authority of the Health Information and Quality Authority (HIQA) be extended to include the regulation, inspection and monitoring of professional domiciliary care providers, which would require amending the Health Act 2007. In addition the report recommends that HIQA develop standards specifically tailored for domiciliary care settings and that such standards should *'… ensure that domiciliary care is provided in a manner that promotes the well-being and independence of the service user in their own home.'*[16] It is important that standards to be applied in people's own homes be respectful of people's rights, dignity and privacy and that monitoring or inspection be undertaken in a manner which fully recognizes the private nature of people's homes. Standards must be applied to both to systems and policies of in-home support providers and to the outcomes achieved by users of their services.

Recommendation:

Standards for in-home support providers with comprehensive monitoring mechanism should be developed and implemented by HIQA.

Standards applied in people's own homes must be respectful of people's rights, privacy and dignity.

Standards must include robust and fully accessible complaints procedures which are independently administered.

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[16] Law Reform Commission *Legal Aspects of Carers* Consultation Paper (2009) p 149

Families and children

The CRPD pays particular attention to children with disabilities and commits State parties to ensuring their equal enjoyment of all human rights. Article 23 (Respect for the family) recognizes the family as the natural place for children with disabilities and commits State parties to the provision of '*… early and comprehensive information, services and support to children with disabilities and their families'*.

A) Family-centered focus

Most people with disabilities live at home with their families and families are the first and most important means through which people make connections with extended family and within their community. Supporting families is key to ensuring the success of the individualization agenda. The CDLP welcomes the emphasis on the provision of family and child-centered supports and services to children in mainstream settings and the central recommendation that families be supported to care for their child at home.

In applying the principle of mainstreaming to services, particularly therapeutic services, for children with disabilities the HSE has re-organised many of these services within integrated disability specific/mainstream health service teams. Prior to this most services for disabled children were accessed through disability service providers' multi-disciplinary teams. While the quality of the individual therapeutic supports was not in question, the segregated nature of the service provision is raised as an issue. It is vital that the reconfiguration of these teams retain the family-centered focus as specified in the policy proposal and that they be inter-disciplinary as opposed to multi-disciplinary in nature. In a review of the literature on the concept of family-centered service delivery Allen and Petr identified the following as among its defining features: retaining the family as the focus of attention, partnership between parents and professionals, relying on family choice and decision-making, emphasizing family strengths and empowering families.[17] The danger of an overly professionalized emphasis is as real in the newly formed cross-agency teams as it was in the disability agency provided services. It is vitally important that the family-centered nature of these new teams is paramount and becomes embedded in the way they operate.

B) Family Leadership

Families may have legitimate fears that a move from traditional services will in fact mean that their family member instead receives less or poorer quality support. It is important that families be fully consulted and involved in the transition and that their long term commitment to, and concern for, their family member by fully recognized. The real concerns of families must be addressed and it is important to build on the potential for families to lead on community

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[17] Allen, R. and Petr, C. *Toward Developing Standards and Measurements for Family-Centered Practice in Family Support Programs* p63-63 in Singer, G., Powers, L. and Olson, A (Ed) **Redefining Family Support: Innovations in Public-Private Partnerships,** Baltimore 1996

connecting and participation. As noted by Power *'Facilitating family leadership should … be a focus of Irish government and third party efforts to support family capacity-building and resiliency.[18].* Whole-system change will involve not alone changes in government policy, but also the active participation of those most centrally committed to ensuring good lives for people with disabilities, most especially family members. Strong family networks and advocacy groups can be key sources of sustained pressure for change and improvement within systems. In addition family-to-family support is of great benefit to people in navigating their way through social service and health systems and in fostering creativity in the development of individualized services and supports for disabled people.

Efforts to develop family networks and family leadership needs to be incorporated into the planning and implementation of the new policy from the outset. This includes building the capacity of families as advocates for their own family members, but also the capacity to lobby for change and to contribute effectively to legislative and policy change and improvement.

C) Families as natural support

The policy proposal envisages that people who need support to live their lives well will receive this support in the first instance from family/natural support systems, secondly from wider community-based informal supports and lastly from formal supports including mainstream and specialized supports. This is a welcome vision and it should help ensure that people remain connected to family and community while getting the formal supports they need to do this. It will also counteract the trend towards isolation and segregation in the existing system whereby people who need formal supports can access this only (or mainly) through a specialist disability service provider. However, it must be remembered that, as noted in the new policy, most people with disabilities live with their families who often provide support to people on a 24 hour basis and that this ' *has been central to keeping many children and adults with disability out of residential services.'* While the policy recommends that people living with family will have access to support packages, it is important that natural supports are not used in any way to replace the formal supports which the person needs. We know from the NIDD that '*The majority of adults with intellectual disability continue to live with their families. As these caregivers age beyond their care-giving capacity, residential supports are required. Additional therapeutic support services are also required for people who wish to continue to live with their families and to live as independently as possible.* [19]. This is a situation which puts enormous pressure on families at every stage of the lifecycle. Counting on the ability of families to provide support, especially where their family member has severe or profound disabilities, cannot be a substitute for the provision of formal support. There is a risk that the willingness and good will of parents and families to provide support will be stretched to levels which are unsustainable. The role

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[18] Power, A. *Active Citizenship and Disability: Learning lessons in transforming supports for persons with disabilities* Centre for Disability Law and Policy NUI Galway (2011) P11
[19] See NIDD Annual Report 2010 P29 and Table 3.2

of the State must be to support people to achieve the maximum level of choice and independence, while at the same time supporting families to provide natural supports. It is imperative that the on-going need of many people with disabilities for formal supports in the process of individualization be fully recognized and that natural supports not be used as a cheaper alternative in a way that undermines families.

Recommendations:

A family-centered focus should be fully adopted and embedded in inter-agency and inter-disciplinary teams working with children with disabilities and their families.

Family networks and family leadership should to be incorporated into the planning and implementation of the new policy from the outset. This includes building the capacity of families as advocates for their own family members and the capacity to lobby for change and contribute effectively to legislative and policy change and improvement.

The need of many people with disabilities for formal supports in the process of individualization must be fully recognized and natural supports provided by families should not be seen as a substitute.

Untangling Social and Health Supports

In the main, people with disability are not ill and where they do have health problems, whether related to their disability or not, these should be dealt with within mainstream health services. Many people with disability, however, require social support of various sorts to live full and independent lives in their communities. At present all funding for disabled people, with the exception of income support, is channeled from the Department of Health where it is sanctioned by the Disability Services Programme Budget through the health vote. Thereafter funding is transferred to the HSE and from there to disability service providers. Disability service providers have generally provided 'wrap around' services where people receive all of their supports from the one agency – including social supports, social work, psychology, occupational therapy and other directly health-related support. This has made the task of 'unbundeling' funds for different aspects of an individual's service extremely difficult.

The question of whether funding for social support through the health budget and health service structures is the appropriate route was addressed by the Commission on the Status of People with Disabilities in 1996 when it stated that ' *it is important to make it clear that these services (respite care, home help, etc,.) are social rather than health services. This is not just a change of terminology but underlines the need to change from a medical and caring model of services towards one based on meeting the social needs of people with disabilities.'[20]* The Commission recommended that structures which are separate and distinct from health be put in place for the delivery of social supports to disabled people – although they suggested that this remain under the aegis of a re-named Department of Health and Social Service.

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 as a vehicle for the delivery of social support funding should be actively explored. As long as funding for health and social support derive from the same department and is channelled through the same systems, 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. In this scenario it is likely that social support services are more likely to lose out. 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 disabled people to live independent lives. Where there is competition for limited

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[20] *A Strategy for Equality, Report of the Commission on the Status of People with Disabilities,* Government Publications 1996, Accessed at
www.nda.ie/cntmgmtnew.nsf/0/9007E317368ADA638025718D00372224/$File/strategy_for_equality_06.htm

resources social services are likely to be the comparatively more vulnerable to budgetary cutbacks.

In addition, and perhaps more importantly, this funding framework makes the adoption of a truly social model approach much more difficult that it needs be. Health services are, by definition, medically orientated. When social support services are incorporated as part of a health service, the influence of the overall medical/health philosophy will undoubtedly have an influence on those services, regardless of efforts to instill social model values. Adopting a social model approach, as outlined in the new policy proposal, is hindered by the intertwining of social and health supports in the current funding framework. It is suggested that delivery mechanisms for these distinct types of services be separated from each other and that consideration be given to whether the Department of Social Protection is the appropriate funding vehicle for social support services.

Recommendations:

The delivery mechanisms for health and social support services should be separated from each other.

Consideration should be given to designating the Department of Social Protection as the appropriate funding vehicle for social support services.

Individualisation and Housing

Article 19 of the CRPD states that people with disabilities have the right to choose where and with whom they live and it ensures that people are not obliged to live in any particular living arrangement. In the area of housing, Article 26 ensures that people with disabilities have an adequate standard of living, including adequate housing. In addition the Irish State has important obligations in this area arising form Article 11 of the International Convention on Economic, Social and Cultural which was ratified Ireland in 1989, and which are equally applicable to disabled people. The elements of adequate housing include legal security of tenure, availability of services, facilities and infrastructure, affordability, habitability, accessibility, location and cultural adequacy.[21] It is important that these aspects are ensured for people with disabilities in the move towards the individualization of services and supports.

The crucial role of housing in people's well-being was recognized in the report of the Commission on the Status of People with Disabilities which states that '*Housing provides much more than shelter in modern society: it is the base from which people participate in society and can reflect as well as dictate their level of participation*'[22]. The report goes on to outline that for disabled people accessibility of housing and the wider environment must be addressed alongside the need for services, supports and income to enable independent living. It is clearly envisaged in the new policy that people will have access to the same housing choices as the rest of the population and that they will have the supports needed to live as independently as possible in their homes. This is very much welcomed.

Whether people currently live in some form of congregated setting, an institution or a group home there will be costs involved in enabling people to move into individualized arrangements which support independent living. It is not possible to simply move funding from the existing structures into new structures. The need for 'hump funding' during the transition from institutional to community living is identified in the new policy proposal.

Both the new disability policy and the Housing Strategy for People with a Disability People will mean the people will access housing through the ordinary routes available to the rest of the population including social housing, the private rental sector or home ownership. This has important budgetary implications for other government departments as well as the Department of Health. In particular the Department of Environment, Community and Local Government (via Local authorities and housing associations) will be the providers of housing and the Department of Social Protection will be the source of rent support.

At present people living in group homes or institutions generally contribute a certain amount to the day-to-day running costs of the house (electricity, heating

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[21] *The right to adequate housing (Art.11 (1)) 13/12/91. CESCR General comment 4.*
[22] *A Strategy for Equality, Report of the Commission on the Status of People with Disabilities,* Government Publications 1996, Section 12.1 Accessed at www.nda.ie/cntmgmtnew.nsf/0/9007E317368ADA638025718D00372224/$File/strategy_for_equality_06.htm

etc) while the costs of maintaining the building is paid from state funds. As people move out of these types of living arrangements the housing costs, in terms of maintenance and renovation of buildings, will be replaced by the need to support the housing costs of people in their own homes. In particular people will need to have increased access to rent support payments. This will mean a re-allocation of funding from the Department of Health to the Department of Social Protection and the Department of Environment. An important issue which needs to be addressed is the inconsistent manner in which people's eligibility to Rent Supplement or the Rental Accommodation Scheme is currently assessed across the state. In some areas people leaving residential care are deemed eligible for these supports while in others they are deemed ineligible. It is recommended that this issue be resolved immediately as it presents an immediate blockage to the implementation of the new policy.

In 2009 15,663[23] adults were recorded on the National Intellectual Disability Database as living at home with family (the majority with parents or siblings), in group homes or in residential settings. A further 764[24] people were recorded on the 2009 National Physical and Sensory Disability Database as living in full-time residential services. This means that potentially at least 16,427 people who could avail of individualized funding, could become eligible for housing and for housing support from the state. This, as suggested by Bostock and Gleeson[25], is a major re-housing programme. They identify the dis-connect between the two key policy domains of disability and housing as the major problem which confronted the de-institutionalization process in Australia. They suggest that housing is *'… treated as a subsidiary issue in community care. Yet, control over where, how and with whom one lives is crucial to a sense of social inclusion. Nevertheless, the fundamental role of housing within community care policy has yet to be fully articulated. … Community care, therefore, can no longer be seen as a specialist area tangential to mainstream housing policy.'[26]* It is acknowledged also that housing and where a person 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 new disability policy in order that people can realize their right to independent living and community participation.

Since the publication of the new disability policy proposal 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. All three policy documents propose the establishment of national and regional implementation structures. People with disability are already subject to a myriad of

[23] *Annual report of the national Intellectual Disability Database Committee 2009.* Health Research Board, Dublin (2010) Table 3.3 P39

[24] *Annual Report of the National Physical and Sensory database Committee 2009* Health Research Board, Dublin (2010)Table 4 P24

[25] Bostock, L & Gleeson, B. *Contested Housing Landscapes? Social inclusion, deinstitutionalisation and housing policy in Australia.* **Australian Journal of Social Issues** Vol. 39, No. 1. February 2004

[26] Health Research Board, Dublin (2010)Table 4 P24

[26] Bostock, L & Gleeson, B. *Contested Housing Landscapes? Social inclusion, deinstitutionalisation and housing policy in Australia.* **Australian Journal of Social Issues** Vol. 39, No. 1. February 2004 p56

administrative assessments in order to establish needs and entitlements, which is way beyond that which is required of non-disabled people. It is recommended that the planning, implementation and monitoring of all three be coordinated effectively so as avoid overlapping of structures, make best use of resources and ensure that people with disabilities can easily access and participate in these systems in a way which is fully person-centered.

Recommendations:

The inconsistent application of the eligibility rules for rent supplement and the rental accommodation scheme across the country should be resolved immediately.

Housing providers, in particular the Department of Environment and local authorities, should be included as critical partners in the implementation of the new disability policy.

The proposed structures for planning, implementation and monitoring of the new disability policy, the Housing Strategy for People with a Disability and the Congregated Settings policy should be integrated and coordinated effectively

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Transition and implementation

Managing the transition from block-funded services to individualized supports is a complex task which, as Power highlights, '...*is not simply a case of replacing one set of buildings or mechanisms with another. Successful community-based support needs to be carefully planned around the needs and wishes of individuals and then continually monitored and adjusted as people's needs and wishes change.*'[27] The success of the transition will depend on the extent to which several critical factors are taken into account and included in the process. Two factors in particular are identified as essential elements of a successful transition from institutional provision to community-based supports[28]:

A)   The adoption of a vision and a strategy for change inclusive of all stakeholders.
Government has a central role in providing the vision and leadership for change - including providing incentives for change, stopping building new institutions and building consensus for change across government, disabled people organisations and advocates. The proposed policy is central to this vision-building and leadership. Key to this, as identified by Power in his analysis of transition processes in the UK, the US and Canada, is the need to include all individuals and organisations interested in the process and ensuring no stakeholder is seen as a barrier to or hindrance[29]. It is important in this context that existing disability service providers are included and are not seen as the villain of the piece. There is a need to recognize that the current structures exist because government and society facilitated and supported them and that everyone, therefore, has a responsibility in this – both for the existence of segregated services and for changing services. On a practical level too, alienating existing providers could create major blockages in the form of industrial relations issues and opposition form staff and communities which are reliant on disability service providers as important sources of employment.

B)   Embedding the voice of people with disabilities

The new policy envisages that disabled people will be central to all new services and supports and that they will be designed in a way which places their aspirations and needs at the heart. However, 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. The evaluation of the Robert Wood Johnson Foundation *Self Determination for People with Developmental Disabilities* programme in the US suggested that in fact '*Consumer involvement in changing systems of health care delivery may need to be*

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[27] Power, A. *Active Citizenship and Disability: Learning lessons in transforming supports for persons with disabilities* Centre for Disability Law and Policy NUI Galway (2011) P14
[28] Mansell J, Knapp M, Beadle-Brown J & Beecgam J. *Deinstitutionalisation and Community Living – Outcomes and Costs: report of a European study, Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, UK.* (2007) pp100-104
[29] Power, A. *Active Citizenship and Disability: Learning lessons in transforming supports for persons with disabilities* Centre for Disability Law and Policy NUI Galway (2011) PP15-16

mandatory for change to take place.'[30] Mansell et also recommends that government work to strengthen the collective voice of people with disabilities, their families and advocates including appointing disabled people to official bodies, building the capacity of Disabled People's Organisations and advocates to contribute to policy-making and requiring policy makers to meet regularly with disabled people. A greater emphasis and commitment to this area would be a welcome addition to the new policy.

This approach is supported by the CRPD which requires in Article 4 that State parties ' *closely consult with and actively involve persons with disabilities, including children with disabilities*' in the drafting of any legislation and policy affecting them.[31] The ongoing provision of advocacy support to enable people with disabilities to express their views and assert their rights is a crucial element in the success of any disability policy reform. A National Advocacy Service is already in place which could contribute to this process, but other forms of advocacy - including self-advocacy, peer advocacy and citizen advocacy - should also be promoted to achieve this. In addition, the National Advocacy Service is currently operating on a non-statutory basis, but legislative provisions could be commenced to provide statutory powers to personal advocates in carrying out their work.[32] The introduction of such powers would provide a crucial safeguard for the process of individualization as advocates could ensure that individuals and families are properly supported throughout the process of transition.

Recommendations:

The new policy should adopt a strategy which includes all stakeholders, works in genuine partnership and avoids isolating any stakeholders.

The voice of people with disabilities should be embedded in the development and implementation of the policy.   The building of the capacity of self-advocacy groups and other forms of advocacy to participate in and contribute to policy and systems development should be an integral part of the policy.

Legislative provisions to give statutory powers to personal advocates in the National Advocacy Service should be made.

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[30] Robert Wood Johnston Foundation (2007) Self-Determination for People with Developmental Disabilities, RWJF. P20 Accessed at http://www.rwjf.org/files/research/CCD.final.pdf 31.10.2011
[31] Article 4(3), CRPD.
[32] Citizens Information Act 2007.

Recommendations

1. The individualisation of funding should be accompanied by robust legal capacity legislation, which recognises the validity of supported decision-making in all aspects of life. 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.

2. The emphasis of the policy on the individual's right to choice and participation should be maintained throughout and avoid any stipulation with regard to numbers of people who can be accommodated together.

3. Where people are availing of individualized funding consideration should be given to how to safeguard people's income and supports in the context of overall government cutbacks, given the particular difficulties people with disabilities encounter in pursuing their rights through the courts.

4. The recommendation that disability service providers no longer establish or run housing associations should be re-considered. Instead consideration should be given to the option of encouraging housing associations currently operated by disability service providers to broaden their board membership.

5. The needs assessment should be fully comprehensive of all domains of a person's life, including the education. Consideration should be given to incorporating educational needs assessment under the EPSEN Act with the supports needs assessment process outlined in the policy proposal.

6. Support or life planning, focused on people's goals and wishes, should be separate from the day-to-day management of people's supports.

7. The definition of mainstreaming should encompass the provision of supports to enable people to access generic services and facilities, the provision of reasonable accommodation by mainstream providers to ensure full access and participation and the design, modifications or adaptations of mainstream services and facilities themselves.

8. The emphasis on mainstreaming and independence should not overshadow the situation of people who are highly dependent and will require long-term specialist supports.

9. Standards for in-home support providers with comprehensive monitoring mechanism should be developed and implemented by HIQA.

10. Standards applied in people's own homes must be respectful of people's rights, privacy and dignity.

11. Standards must include robust and fully accessible complaints procedures which are independently administered.

12. A family-centered focus should be fully adopted and embedded in inter-agency and inter-disciplinary teams working with children with disabilities and their families.

13. Family networks and family leadership should to be incorporated into the planning and implementation of the new policy from the outset. This includes building the capacity of families as advocates for their own family members and but the capacity to lobby for change and contribute effectively to legislative and policy change and improvement.

14. The need of many people with disabilities for formal supports in the process of individualization must be fully recognized and natural supports provided by families should not be seen as a substitute.

15. The delivery mechanisms for health and social support services should be separated from each other.

16. Consideration should be given to designating the Department of Social Protection as the appropriate funding vehicle for social support services.

17. The inconsistent application of the eligibility rules for rent supplement and the rental accommodation scheme across the country should be resolved immediately.

18. Housing providers, in particular the Department of Environment and local authorities, should be included as critical partners in the implementation of the new disability policy.

19. The proposed structures for planning, implementation and monitoring of the new disability policy, the Housing Strategy for People with a Disability and the Congregated Settings policy should be integrated and coordinated effectively

20. The new policy should adopt a strategy which includes all stakeholders, works in genuine partnership and avoids isolating any stakeholders.

21. The voice of people with disabilities should be embedded in the development and implementation of the policy. The building of the capacity of self-advocacy groups and other forms of advocacy to participate in and contribute to policy and systems development should be an integral part of the policy.

22. Legislative provisions to give statutory powers to the National Advocacy Service should be made.