VALUE FOR MONEY AND POLICY REVIEW OF DISABILITY SERVICES

A: BACKGROUND INFORMATION

If you are responding on behalf of an organisation (including a body which provides disability services), please give the name of the organisation and your role:
Centre for Disability Law and Policy, NUI Galway
Dr Andrew Power, Researcher

B: OBJECTIVES

Within the framework of *Towards 2016*, the high level objectives of the disability services funded from the HSE Vote (No. 40) may be summarised as being:

1) To provide the individual with a disability, to the greatest extent possible, the opportunity to live a full and independent life with their family and as part of their local community.
2) To support the individual with a disability, as far as possible, to participate in work and in society and to maximise their potential.
3) To ensure that the individual with a disability would, consistent with their needs and abilities, have access to appropriate health and personal social services.
4) To support and acknowledge the role of carers in their caring role.

B1. In your view, are the objectives for the disability services programme still relevant to the needs of people with disabilities?

Significantly relevant ✓
Partially relevant
Of little relevance
No relevance
Don't know

B2. Please give reasons for your answer:
The Towards 2016 framework high level objectives provide an important vision for ensuring that individuals have the opportunity to have a full and independent life. The implementation of this however requires a significant and sustained commitment at addressing the structural inefficiencies in the system. These goals are also central to our National Disability Strategy and

the funding allocated to disability services as part of the Multi-Annual Investment Funding Program.

From an independent living perspective, certain commitments outlined in the Towards 2016 Agreement are of particular importance. These include a commitment that person-centred supports will continue to be developed for long stay residents in psychiatric hospitals, with a view to their movement back into community living and also a commitment that person centred supports will continue to be provided to adults with significant disabilities having regard to the range of support needs which they require, e.g. nursing, personal assistance, respite, rehabilitation, day activities etc.

If you answered OF LITTLE OR NO RELEVANCE, can you suggest more relevant objectives?
B3.

B4. In your view, have the objectives of the disability services been met?

a. To provide the individual with a disability, to the greatest extent possible, the opportunity to live a full and independent life with their family and as part of their local community.

To some extent

b. To support the individual with a disability, as far as possible, to participate in work and in society and to maximise their potential.

No

c. To ensure that the individual with a disability would, consistent with their needs and abilities, have access to appropriate health and personal social services.

To some extent

d. To support and acknowledge the role of carers in their caring role.

To some extent

B5. Please give reasons for your answer:
While there are some areas of grass-roots good practice across the country, these are not being recognised or encouraged by any national guiding mechanism. A new policy climate must be implemented which provides innovative commissioning of good practice models. The roles for each

stakeholder and type of service provider must be made clearer. A clear demarcation must be made between housing, health needs, social needs.

In relation to Carers, although the Carer's Strategy was developed by the Department of Social and Family, this was not published and therefore there is currently no coherent policy framework for achieving this aim of Towards 2016.

A significant step towards ensuring that persons with disabilities could participate in work and society was made by the pilot Disability Activation program developed by the Department of Social and Family Affairs and the Department of Enterprise, Trade and Employment. However, this programme has not been rolled out beyond its pilot phase.

B6. Do you have any other comments you wish to make on the OBJECTIVES of the disability services provided by the HSE or voluntary service providers?

C: EFFECTIVENESS

Effectiveness is defined as the delivery of planned benefits in the short to medium term and the extent to which objectives were achieved in the short to medium term.

C1. In your view, are the range of services being delivered still relevant to the needs of people with disabilities?

Significantly relevant
Partially relevant ✓
Of little relevance
No relevance
Don't know

C.2 Please give reasons for your answer:

While some service providers are creatively orienteering themselves towards community development and fostering personal plans, many are still operating with inappropriate residential and congregated service infrastructure.

C3. Do you feel that the range of services available is having a positive impact on the lives of the people who use them?

Significant impact
Partial impact ✓
Little impact

No impact
Don't know

C4. Please give reasons for your answer:
The recent drive toward person-centred planning has had a significant positive effect on persons with disabilities. However, this practice needs to become standardized across all services with an emphasis on community connecting and mentoring schemes, such as Big Brother, Big Sister.

C5. Has there been a change in the quantity, range or quality of services offered to people with disabilities over the last five years?
Increased/Stayed the same/Decreased/Don't know

a. Quantity of services

Stayed the same

b. Range or variety of services

Increased

c. Quality of services

Stayed the same

C6. Please give reasons for your answer:
Despite the commitment towards multi-annual funding, the HSE has had trouble allocating much of this funding because of infrastructural inefficiencies and other priorities.

Despite these challenges, the range and variety of new options has increased with good practice models such as the regional CIL's, service management peer support such as New Options Alliance.

C7. How satisfied are you with the following:
Very Satisfied/ Satisfied/Neither Satisfied or Dissatisfied/Dissatisfied/Very Dissatisfied

a. The amount of choice people with disabilities have over the services they receive from service providers?

Dissatisfied

b. The independence people with disabilities have in how they live their lives?

Dissatisfied

c. The amount of control people with disabilities have over their lives?

Very dissatisfied

d. The support people with disabilities receive from service providers to facilitate their inclusion in the mainstream life of the community?

Dissatisfied

C8. If you think that people with disabilities should have **MORE CHOICE IN THE SERVICES THEY RECEIVE** from service providers, what are the top three changes that would help bring this about:

1. Individualising funding based on functional assessment criteria as well as personal planning tool needs to be implemented. E.g. the DOORS model in Wyoming uses both standardised tools as well as personal planning interview. It is regarded as the most successful model in the US jurisdiction. Alternatively, the International Classification of Functioning (ICF) is being developed as a leading world-wide tool for assessing the needs of persons with disabilities.

2. Direct funding should also be an option for persons (with the input of their families if needed) who have the capacity to arrange their own services. However this only works if the individual is supported in making these decisions (see C9 below)

3. The work by New Options Alliance is a positive development in the disability field of promoting individualised options. This provides the space for service providers who are interested in designing individualised supports to troubleshoot issues, discuss best practice, and encourage the knowledge transfer with people with external expertise. The government should foster a developmental environment, which incorporates capacity building activities, best practice commissioning and an advisory counsel.

C9 If you think that people with disabilities should have **MORE SUPPORT IN ENABLING THEM TO HAVE CONTROL OVER THEIR DAY-TO-DAY LIVES**, what are the top three changes that would help bring this about:

1. Independent Planning: Each disability service provider agency should ensure that planning is done in a separate department and involve an independent advocate/consultant as well as the family. This would ensure that persons with disabilities gain from a holistic perspective with a focus on community options available.

2. Comparatively in the US and Canada, direct funding is regarded as only successful when the person is supported by a fiscal intermediary (FI). A FI provides the government with an accountability monitoring tool, as well as providing the individual assistance with payroll, tax etc. The CIL's, as is the case in Northern Ireland, would provide a suitable 'host' for providing this FI role.

3. Reform in the legal framework for substitute decision-making is currently underway in Ireland and this will significantly enhance the level of choice and control people with disabilities have over their day-to-day lives. However, the proposed Mental Capacity Bill should also recognise less restrictive alternatives to guardianship for people with decision-making disabilities, such as supported decision-making and personal advocacy.

C10 If you think that people with disabilities should have **MORE SUPPORT ENABLING THEM TO LIVE AN INDEPENDENT LIFE**, what are the top three changes that would help bring this about:

1. The introduction of the Personal Advocacy Service envisaged in the Citizens Information Act 2007 would assist with this process, since advocates assist persons to obtain essential social services which are necessary to promote independent living.

2. The commencement of the CQL accreditation process for personal outcome measures and HIQA guidelines on Residential Services for People with Disabilities would ensure that people are supported to live as independently as possible. Alternatively, a new investigative mechanism could be introduced for those in residential care, similar to the volunteer-operated Community Visitors Program which has operated successfully in the Australian state of Victoria.

3. With the projected increases in elderly and disabled populations in Ireland, the increasing prevalence of diseases and declining capacities in older people are leading to a rising demand for care services. While the home is generally the preferred site of care, the risk of accidents around the home in many cases, leads to unwanted institutionalisation. In these cases, home

modifications (both low- and high-technology) allow for an extended and safer use of the home for independent living. In terms of the costs and consequences, various non-expensive forms of modifications exist, such as information and communication technologies (ICT), telecare, assistive technology services and smart homes for older and disabled people in Ireland. British Telecom in England for example have successfully piloted the development of safe homes with tele-care technology in Liverpool. This sector, largely led by Intel in Ireland, as well as various telecom and electronics manufacturing companies, would benefit from a government commitment which supports the realisation of the potential these home-care technologies hold as an integrated, proactive, health-enhancing intervention in the care of older and disabled people in different care situations and settings. Supporting Ireland's edge in technology both creates business and enhances independence for people with disabilities.

C.11 If you think that people with disabilities should have **MORE SUPPORT TO FACILITATE THEIR INCLUSION IN THE MAINSTREAM LIFE OF THE COMMUNITY**, what are the top three changes that would help bring this about:

1. Community connecting - the practice of enabling people with learning disabilities connect with individuals and local organisations in their community; find voluntary and/or paid work; and more generally to lead full and purposeful lives in their communities and to develop a range of friendships, activities and relationships. In other jurisdictions, Community Connecting has been a very successful, cost-effective and sustainable method of supporting individuals in the community, as it fosters natural supports around the person, rather than relying solely on expensive state-run agency services. Examples include the PLAN Institute in British Columbia, Canada (which operates on a fee-for-service basis), and In Control (which has a fee-for-service and/or individual budget approach) in the UK.

2. Activation Programmes – such as that piloted by the Department of Social and Family Affairs with the Department of Enterprise, Trade and Employment – could be rolled out gradually on a nationwide basis.

3. Moving away from a process of deinstitutionalisation to ensure that community living is the direction that current policies on disability promote. Given the success of the Carmichael House INCARE pilot and subsequent nationwide roll-out, the clarification of policy on Personal Assistance Services would also be useful for this.
At present, the provision of support services to enable people with disabilities to live independently in their own homes, such as Personal Assistant Services and Home Help Schemes is problematical. Despite the identification of such

services as fundamental to facilitating independent living for people with disabilities, they remain underdeveloped. Furthermore, access to such services is uneven given waiting lists of differing lengths across the country. The government cannot save money by cutting back on these services, because without a sufficient network, unwanted institutionalisation will remain.

C12. Are there measures which could be taken (whether alternative policies or organisational approaches) to improve effectiveness, taking into account service to the user and value for money?

Yes ✓
No
Don't know

C13. If you answered yes, please give reasons for your answers with specific examples:

a. Alternative policies:

Developmental model: as envisaged by NESC report on the Developmental Welfare State. This outlines the importance of activist or innovative measures- and that these should be integrated to form a 'developmental welfare state'

Lifecycle approach: The lifecycle approach has already been formally adopted in government policy (e.g. Towards 2016, National Action Plan on Social Inclusion, etc.) but now needs to be rolled out in all policies and programmes developed at departmental level. This will require significantly more cooperation between departments related issues where responsibility has been divided – e.g. education and employment, transport and environment, etc.

b. Alternative organisational approaches:

Rather than a command-and-control mechanism for procuring services, which is beginning to occur in the wake of the VFM audit, the local authorities should focus on innovative commissioning. Rather than using a global funding mechanism, in which staff costs, transport, and costs for new schemes remain opaque, the local authorities need to provide more targeted funding based on HIQA national standards and CQL measurement, and improvement of personal and community quality of life outcomes.

One potential reform option could be to introduce legislation regulating disability services (both state services and voluntary services funding by

public monies) as has been achieved in the Australian State of Victoria with the Disability Act 2006. This legislation requires registered service providers to adhere to statutory principles to promote independence of persons with disabilities, provide information on service delivery options and ensure access to an independent advocate where necessary to facilitate decision-making about service delivery.

All research and expert opinion from the US and Canada show that a shorter deinstitutionalisation transition process results in lower overall costs than a longer dual-system. When states are closing institutions, there is a period during closure when the per-person expenditure increases1. At the same time there must be expansion of services in the community. One seminal study2 compared per diem institutional costs in US states that had dramatically reduced or closed institutions between 1988 and 2000 to per diem costs in states that had very minor declines in institutional populations during the same years. This study found that the high-change states had a greater initial increase in per-person costs in their institutions than did the low-change states. However, their overall state institutional expenditures were lower over the same duration because their institutional populations declined rapidly, bringing their overall expenditures down quicker than a dual institution-and-community structure. In this case, those states that closed institutions had no institutional per diem after closure and were able to spend all of their annual allocation in the community.

C14. Please outline any specific examples of services which are particularly effective in meeting the needs of people with disabilities:

St. Mary's BC is an agency which began as a residential service provider for people with ID. In 1983, it began a process of reshaping itself into an organisation.
In a series of meetings with families and individuals, a number of changes were initiated.

OPTIONS, Toronto (a program ran by Family Service Toronto). They help create natural networks, mentors, skill developers and door-openers that all people depend on. They have created several Community Initiatives

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[1] 'All People Can Be Supported In The Community' toolkit http://thechp.syr.edu/toolkit/

[2] Stancliffe, R.J., Lakin, K.C., Shea, J.R., Prouty, R.W., Coucouvanis, K. (2005), "The economics of deinstitutionalization", in Stancliffe, R.J., Lakin, K.C. (Eds),Cost and Outcomes of Community Services for People with Intellectual Disabilities, Paul H. Brookes Publishing Co., Baltimore, MD,

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including: Independent Seekers Group, Best Buddies etc.

IRIS (Include, Respect, I Self-direct) is a new Wisconsin long term care option that began July 1, 2008. Individuals are offered the choice of IRIS or managed care when they enter the state publicly funded long term care system. Persons using IRIS are able to self manage their goods and services and may use IRIS to remain in their community and avoid moving into a nursing home or an institution.
With IRIS, adults have control over the type of services they receive in home and community settings and can use their individual budget for functional, vocational, medical and social needs. A key IRIS feature is the participant or their family member or representative being in charge of their long term care and fully self-directing their services, can self-direct their own supports in their life.
The process starts with the individual selecting their own IRIS Independent Consultant with help from the IRIS Independent Consultant Agency. The IRIS Financial Services Agency pays the bills for services received that the person authorizes according to their written IRIS plan. Help from both of these IRIS agencies is provided at no cost to the person's plan and monthly budget. They may enlist the help of a support broker if desired, and support broker fees are paid out of your individual monthly budget allocation.
IRIS participants then create a support and service plan for their long-term care supports and services within an individually assigned monthly budget allocation. The monthly budget allocation may be adjusted based on an individual's unique circumstances. In IRIS the individual chooses the services they need, and decides where and how to spend their monthly IRIS budget allocation. They may hire their own service workers directly or they may purchase goods and services from an agency provider.

Consortium for Employment Success (CES) Model. In Syracuse University, New York, this model was established as a consequence of finding that many employers welcomed thoughtful, timely, effective support in meeting their personnel needs when dealing with disability related issues. Moreover, while it is clear that employer attitudes are in part to blame for the high unemployment of people with disabilities, various studies found that employers expressed a willingness to hire people with disabilities but often did not because they perceived applicants with disabilities as being unqualified or were unable to recruit them. While these employer perceptions may be in part self justification, they might also point to the broader challenge of finding ways to narrow the gap between consumers and employers.

In response, to meet the dual needs of employers (who would like one point of contact), and providers (who perceive themselves as already over-extended) they developed the Consortium for Employment Success (CES)

Model in order to utilise a more structured form of collaboration through a set of stages, which evolved overtime. These stages – co-existence, communication, cooperation, coordination, and collaboration - involved slowly building partnerships with local employers and local employment support agencies. One key constituent of the CES is the Memorandum of Understanding. This outlines the expectations and responsibilities of each agency, including the resources they agree to allocate to the CES. As a means of demonstrating their willing involvement in the CES, each partner agency is required to sign the MOU. The MOU also allows for an assessment of the agency's overall compatibility with the CES.

In partnership, agencies have access to many more employers than they would individually. Employers profit by having a single point of contact, and an easy method to tap into the labor supply of people with disabilities who are often qualified and motivated workers. And individuals benefit by having access to a broader range of quality employment opportunities. This also has important implications in the mental health SE system, as the largest service delivery barrier is fragmentation among mental health, employment, and vocational rehabilitation providers. It thus offers the opportunity to coordinate information and correspondence at the interface between employer and disability point of contact.

D: EFFICIENCY
Efficiency is defined as optimising the ratios of inputs (resources used) and outputs (services produced).

D1. To what extent are current staffing levels appropriate for the efficient delivery of the services?
Too high/Appropriate/Too low/Don't know

a. Nursing

Too high

b. Allied Health and Social Care Professionals (e.g. physio, speech and language and occupational therapist, social workers, house parents, audiologists, dieticians, psychologists)

Too low

c. Other Patient/Client Care (e.g. care assistants, workshop supervisors/instructors, family support workers, outreach workers)

Too low

d. General Support Staff (e.g. home helps, personal assistants, drivers, general operatives, nurses aides, catering officers, cooks, housekeeping staff, porters, laundry staff)

Too low

e. Management/Administration

Appropriate

D2. Please give reasons for your answer:

In comparison with other jurisdictions (e.g. only 8% of entire disability support workforce in Glasgow have professional qualifications), Ireland has been its own worst enemy in terms of over-professionalising the disability care workforce. The future care workforce in Ireland will have to be re-shaped to support people living in community homes or family settings. This will involve a large labour market restructuring process towards home care attendants. This would look more like the home care sector for the elderly. At present, the HSEAs are not geared up for meeting this requirement.

In terms of management staffing levels, a more innovative commissioning body would bypass this issue by fostering.

D3. How satisfied are you that the mix of staffing skills as identified at question D1 is appropriate for the efficient delivery of the services?

Very Satisfied
Satisfied
Neither Satisfied or Dissatisfied
Dissatisfied ✓
Very Dissatisfied

D4. Please give reasons for your answer:

Again, in order to meet the objectives of transforming disability supports to…

D5. Is there scope to reduce overhead costs in disability agencies (examples of overhead costs include administrative costs, management structures, research, advertising, profile-building and infrastructure costs)?
Yes/No/Don't know

a. HSE Service Providers

Yes

b. Voluntary Service Providers

Yes

c. Representative Groups

Yes

d. Advocacy Groups

No

D6. Please give reasons for your answers, and specific examples:-

a. HSE Service Providers

Given the recent establishment of the HSE in 2005, the national agency has been in a period of transition, with redefining their role in disability support, alongside primary care. During this period, the dispersal of Multi-Annual

Funding across other HSE priority areas meant that the Strategic Plan of the funding was haphazard.

b. Voluntary Service Providers

There are significant inefficiencies in the funding model for individuals in shared accommodation. For example, in Ireland, if 4 people with mixed level of disabilities live together, there will be 24 support for everyone. Average support hours for disparate group is inefficient and leads to standardised costs (e.g. €20,000 for day care placement, €80,000 for residential placement). In UK generally the move is to more individual support arrangements. Thus in one service in Glasgow, the costs of packages can vary between £15,000 – £147,000, which is much more cost-effective.

c. Representative Groups

d. Advocacy Groups

D7. How satisfied are you with the QUALITY OF SERVICES being provided to people with disabilities?

Very Satisfied
Satisfied
Neither Satisfied or Dissatisfied
Dissatisfied ✓
Very Dissatisfied

D8. Please give reasons, with specific examples, for your answer:
The level of congregated services in Ireland, according to the NIID latest report, compared to international standards remains high. The HSE and Office for Disability must ensure a sustained commitment to developing more appropriately sized community residences and supports for persons living at home.

D9. How satisfied are you with the MANAGEMENT OF SERVICES for people with disabilities?

Very Satisfied
Satisfied
Neither Satisfied or Dissatisfied
Dissatisfied ✓
Very Dissatisfied

D10. Please give reasons, with specific examples, for your answer:

There are cases of very good management, with clear goals towards individualising support options, however, more generally, managers of services are too busy with daily administration, financial management and labour issues, to focus on ensuring the rights of people with disabilities are being met. Some organisations are ensuring that lead persons are taking on this role within their services to ensure there is natural community supports are included.

D11. How satisfied are you with the following:
Very Satisfied
Satisfied
Neither Satisfied or Dissatisfied
Dissatisfied
Very Dissatisfied

a. The AVAILABILITY OF INFORMATION regarding the range of services provided?
Dissatisfied

b. The QUALITY OF INFORMATION regarding the range of services provided?
Dissatisfied

c. The ACCESSIBILITY OF INFORMATION regarding the range of services provided?
Dissatisfied

E: FUNDING AND RESOURCES

E1. How satisfied are you that funding is targeted at the right services to achieve the best outcomes for service users?

Very Satisfied
Satisfied
Neither
Satisfied or Dissatisfied
Dissatisfied ✓
Very Dissatisfied

E2. Please give reasons for your answer:
Given the broad scope of the service level agreements, and the global

funding allocations, very little of the funding is individualised to reflect the needs, level of disability, functional ability of the individuals with disabilities.

E3. Please provide any suggestions you have as to how existing resources could be better directed to improve efficiency and effectiveness to deliver better value for money?

The local authority should use an individualised funding tool, like the DOORS model or In Control's Resource Allocation System, to reduce standardised funding bands. Otherwise, inefficiencies emerge where persons with less support requirements receive the same level of funding as those with more profound impairments.

E4. In general, given the choice, which of the following options would best meet the needs of people with disabilities?

One service provider looks after everything for an individual with a disability

People with disabilities can choose their service provider

People with disabilities can choose to get different elements of service from different providers ✓

E5. Please give reasons for your answer:

People should be able to choose to get different elements of service from different providers. Housing should be provided by local authorities (and be given the capacity for this task) or contracted to non-profit agencies focusing solely on this provision. Traditional service providers should focus on personal attendant services and community connecting. Planning should be regarded as a different element and should incorporate the input of advocates.

E6. In general, given the choice, which of the following options would best meet the needs of people with disabilities:-

People with disabilities get to choose and manage their own services ✓

The budget for services for an individual should follow the person if they move service

The service provider receives the budget to provide the service

E7. Please give reasons for your answer:

A disability support model needs to incorporate the *choice* of option A and B. In cases where a person has the capacity and preference to manage their own services, they should be given the tools (direct payment and Fiscal Intermediary) to do this. In cases where a person would prefer a service to direct their support, the money should follow the person if they decide to move service. The HSEA's need to standardise their assessments so that a person can take their allocated funding to another jurisdiction.

E8. Please provide examples of services for people with disabilities which use funding and resources to best effect:

Community Living British Columbia (CLBC) offers the different choices outlined in E6 as standardised options available to all persons with disabilities. They provide direct funding, funding to transfer payment agencies (who arrange the individual's supports), or to a traditional disability agency. CLBC provide a facilitator role (much like a service broker) who plans out the support programme with the individual, their family (and advocate if needed).
While direct payments still remain a small proportion in B.C., in other jurisdictions like Western Australia and the United Kingdom, the rates of individualised funding are between 20%-30%. This significant rate demonstrates the potential for the state to reduce overheads payments.

Thank you for participating in the consultation process.