

National Institute for Intellectual Disability

Submission on Value for Money Policy Review – November 2011

This submission is prepared by the National Institute for Intellectual Disability (NIID), Trinity College Dublin. NIID welcomes the opportunity to respond to the draft policy document emanating from the Value for Money Policy Review. The review provides a unique opportunity to examine the future direction and configuration of disability support services nationwide. NIID is aware that the current policy document pertaining to intellectual disability, Needs and Abilities, was launched in 1990. Within the intervening twenty-one years, the country has experienced extraordinary change. And yet, for some individuals with disabilities, little has changed. The current system of provision is characterised by an outdated model of care based on the medical model of disability. This model represents a bygone era, and it is timely and appropriate that it is replaced by a rights- based model of service delivery tailored to individual need. This is particularly relevant given that Ireland will shortly ratify the United Nations' Convention on the Rights of People with Disabilities.

Do you agree that the current system of delivery of services for people with disabilities needs to be improved?

Yes, NIID supports the paradigm shift that is urgently required in Ireland regarding the delivery of support services for people with disabilities. NIID outlines below some of the changes that are necessary for this to happen.

Do you agree that a move to individualised supports is the right policy to pursue?

Yes, the development of individualised support services is to be welcomed. Clearly, 'one size fits all' services are most unlikely to meet individual need. Individualised services must, however, be appropriately resourced. The development of a supporting infrastructure, including elements such as independent assessment, brokerage and advocacy, is an essential component in the successful implementation of individualised services. Infrastructural development will be also be required within local communities to support those who wish to self-direct their own services and transfer to mainstream services. Throughout this period of transition there will be anxieties, not only from those who avail of services, but also from service providers as to the new landscape of supports. A planned and evidenced-based transition is essential to allay any such concerns and ensure successful implementation.

Do you agree that the definition of individualised supports in the report is adequate and comprehensive?

NIID would recommend that the following issues be incorporated into the definition of individualised supports as presented on p15:

(1) There is no mention in the definition of individualised funding. The allocation of funding by HSE to individuals, as opposed to service providers, is a fundamental

element of individualised services. The distribution of individualised funding, based on individualised need, enables people with disabilities to commission their own supports. This is a fundamental paradigm shift which offers optimal levels of choice and control to individuals. Any move towards individualised funding will need to ensure that a wide spectrum of management options is available, ranging from those who wish to remain with their current support arrangements, through to those who wish to become employers of personal assistants.

(2) The definition should include reference to the continuous assessment of individualised support. Ongoing assessment of an individual's need for support is necessary as needs fluctuate both over time and across different life domains.

(3) The definition should include a requirement that individuals have access to information about their services in an accessible format (e.g., easy to read, pictures-based, a support person who communicates the information, Braille, sign language, etc.). The specific format of information should be the most appropriate for each individual.

(4) The definition makes no mention of how individuals will be appropriately supported to make decisions about their support services based on their individual preferences and/or needs.

(5) The definition should include reference to standards. Despite the development of standards for residential supports in 2009, these have yet to be implemented on a statutory basis. The development and implementation of standards across all aspects of service delivery remain urgent issues nationwide.

How do you feel the Government's policy of mainstreaming has worked so far?

It is difficult to address this question appropriately given that the ongoing monitoring of the National Disability Strategy is not in the public domain. While departmental sectoral plans are published, these are aspirational in terms of progress towards mainstreaming. NIID recommends that mainstreaming targets be formally monitored on an annual basis. This would provide a transparent and timely status on the mainstreaming agenda.

Of particular relevance for NIID is the issue of access to mainstream third-level education for students with intellectual disabilities. NIID delivers a two-year Certificate in Contemporary Living to students with intellectual disabilities at Trinity College Dublin. NIID provides support to an additional five third-level institutes nationwide who deliver similar courses. While the number of third-level courses available to students with intellectual disabilities is modest, new courses are being established on an ongoing basis. Students with intellectual disabilities are not, however, afforded the same rights as other third-level education students. Students with intellectual disabilities are ineligible for mainstream student grants as the courses they attend are at a lower educational level than more traditional third-level courses on the National Framework of Qualifications. As a consequence, services

funded via the student grant, such as the Disability Support Services, are not formally available to students with intellectual disabilities. There is clearly an inequity here whereby these students are deemed ineligible for supports on the basis that the courses they attend are specifically developed at an educational level that best meets their need. These barriers do little to promote the development of mainstreaming as a policy objective.

Do you think a move to individualised supports will further the mainstreaming of services?

Given the choice, and reflecting patterns observed internationally, a proportion of people with disabilities are likely to move away from traditional disability-specific services towards mainstream options.

Do you agree that people with disabilities should have the choice to select different services from different service providers and at a time of their choosing?

If true choice is to be achieved, it is essential that individuals are not tied to a given service on the basis of geographical catchment area to meet their needs. Experiences from the UK would suggest that where housing and direct care supports are typically provided by different support services, people with disabilities can exercise greater choice where one service fails to deliver a satisfactory service. Complaints to a housing authority will not endanger a resident's direct care support, and vice versa. The opportunity to choose multiple providers for different aspects of support is also likely to increase competition between providers and therefore promote the development of services that are attractive to service users. Currently, no competition exists in the disability sector, resulting in limited choice for the consumer.

Even if you are happy that the service currently being provided to a service user is appropriate, do you agree that the overall system of funding has to change to tie in with the need to provide more control and more choice for individuals?

The statement 'even if you are happy that the service currently being provided to a service user is appropriate' suggests a level of misunderstanding regarding the introduction of individualised funding. The introduction of individualised funding does not necessarily impact on the service currently being provided to an individual, if the individual wishes to remain with his/her current service. An array of service arrangements should be made available, including the option for individuals to continue to receive their current service, with all financial management being undertaken by the service agency. NIID is aware of family members in particular being misinformed that the introduction of individualised funding will require them to become employers, with all the responsibilities of recruitment, salaries, and personnel management. NIID recommends that, prior to the introduction of individualised funding, an information campaign is launched to ensure that accurate and accessible information is available.

As people with disabilities make the choice to live in ordinary independent settings which are integrated into their communities, what do you see as the impact of the reconfiguration of existing services on other service users, their families and staff delivering these services?

While there will undoubtedly be disruption to the system during the reconfiguration of service delivery, this transition has occurred in many international jurisdictions. Ireland has late mover advantage to learn from the experiences in these other jurisdictions. The issue for those who use services, their families, and those charged with delivering services is to provide a broad range of support options to ensure that individuals are appropriately supported, irrespective of whether they wish to alter their current support service.