

National Disability Authority's Response to the Report of the Disability Policy Review

Introduction

The National Disability Authority is the independent state body providing expert advice on disability policy and practice to the Minister, and promoting Universal Design in Ireland. The National Disability Authority welcomes the opportunity to respond to the public consultation on the future of Disability Policy in Ireland based on the [Report of Disability Policy Review](#) by the Expert Reference Group on Disability Policy. This brief submission is based upon more detailed content contained in the National Disability Authority's [Advice Paper to the Value for Money and Policy Review of Disability Services Programme](#) in July 2010

The National Disability Authority endorses the vision for disability services set out in the [Report of Disability Policy Review](#), and the proposals on governance, summarised in section 14.9 of the Report. The [Report of Disability Policy Review](#) substantially reflects the strategic direction proposed in the advice paper which the Authority submitted in 2010. This in turn had drawn on significant pieces of work undertaken by the National Disability Authority that had provided evidence for our input, such as:

- A series of focus group consultations, in which a total of about 100 people participated, with people with disabilities, their families, advocates and frontline service providers. Part of this consultation was to illicit the views of people with intellectual disability regarding emerging policy proposals from the Department of Health in relation to the Value for Money and Policy Review of Disability Services (see [Independent and Community Living- the views of people with disabilities, families and front line staff](#))
- A review of systems of disability service provision in six jurisdictions regarded as models of innovation and of good practice,¹ and a detailed study of evidence on outcomes from the United States of America (see [Health and Personal Social Services for People with Disabilities](#))
- Research evidence on quality of life outcomes in different settings
- Learning from site visits to other jurisdictions

¹ England, Scotland, Netherlands, Norway, New Zealand, and the state of Victoria (Australia)

Moving the agenda forward

The National Disability Authority is currently engaged in a number of pieces of work that will be of assistance in guiding on the next practical steps to be taken, if the strategic direction set out in the [Report of Disability Policy Review](#) is adopted. The National Disability Authority has also recently published reviews of relevant evidence on our website on:

- Resource allocation models
- Natural community supports and personal networks

Relevant work in progress, concluding in 2011 and 2012, includes:

- A field trial with 120 service users to compare the main needs assessment and resource allocation models used in the United Kingdom and the United States of America, to help guide the implementation of personal budgets
- An advice paper on Commissioning of disability services, drawing on international models, the evidence, and the learning from an expert seminar organised by the National Disability Authority
- Original research with people with disabilities and with service providers on natural community supports and networks
- Research into the practice of assessment of need under Part 2 of the Disability Act 2005
- Guidance on accessibility of mainstream health services
- A paper summarising the evidence on direct payments
- A paper summarising the current evidence on people with disabilities in universal health insurance systems
- Engagement with a range of Government Departments, on other aspects of the independent living agenda, for example, on universally-designed lifetime homes

Future work programme

The National Disability Authority is currently in the process of finalising its workplan for 2012, and of developing its strategic plan for the subsequent three years 2013–2015. This is a further opportunity to undertake work that can offer practical guidance on the detail of a reconfigured disability support system and on the steps to get there. The National Disability Authority would welcome engagement with the Department of Health on where our work could best make a contribution to advancing this agenda, which can inform the planning of our future work. The National Disability Authority welcomes the suggestion in the policy paper about working with the Centre for

Excellence in Universal Design on telehealth and telecare, and this is being factored into our programme of work.

Managing change – sharing the vision

Moving from current service models to a system of individualised supports will be a major process of change. From our research on other jurisdictions, and engagement with experts there, the National Disability Authority's advice is that a key element in achieving a successful change is to build support among stakeholders for the new vision.

It is, therefore, critical that there is engagement to ensure that as many stakeholders as possible - people with disabilities, their families, services providers and their staff - are made aware of the vision, and provided with adequate opportunities to express their views. In this process, it is important to communicate with people with intellectual disabilities in ways they can understand.

The National Disability Authority's comments on specific questions posed

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

Answer-Yes. The evidence is that available resources could be delivering a better quality of life for service users.

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

Answer-Yes. Tailoring supports to individuals rather than slotting individuals into existing services can deliver a better and more fulfilled life for people with disabilities. This can also deliver a better match between resources and need.

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

Answer-The National Disability Authority agrees with the definition of individualised supports as set out in section 10.3 of the Report of the Disability Policy Review.

However, in describing 'individualised supports', it may be useful to clarify and expand on the following points:

- that funding for a person's disability supports could be moved to programmes or services of their choice and which meet their needs
- how individualised supports might link to individualised funding or to individualised resource allocation

- how individuals (with their families) would be assisted to envision a different life of their choosing and the different kinds of service that could support that life
- how service users (with their families) would be involved in informing the shape of services on offer

Individualised resource allocation

The National Disability Authority suggests that in describing what is meant by 'individualised supports' it should set out more clearly and explicitly that the funding available for individualised supports would be underpinned by a transparent, evidenced-based process. Resource allocation would be based on an assessment of the individual's needs, taking account of the supports available to them.

The National Disability Authority's work on resource allocation models, including the current feasibility study of two major resource allocation tools, will be helpful in developing the concept of individualised funding to the next stage.²

Assistance towards making choices

The evidence from research, and from experience in other jurisdictions, suggests that some people with disabilities and their families would initially need help, in order to envisage the possibilities for the person's life, and the kinds of support that could be made possible by an individualised service model. Assistance to choose might take the form of training, advice, brokerage services or access to peer-led groups. There is a risk that without such assistance to choose, the full potential for user-led services and supports would not be realised, resulting in a low take-up of such options.

Shaping the supply of services

If a system of individualised services is to be successful in achieving its aims, it will be important to engage with service users (and their families) at an early stage of the process. The Health Service Executive, which as the major funder, can help shape the options available, can play a strategic role in commissioning and encouraging the emergence of services that address the identified needs and choices of people with disabilities.

A move towards a model of strategic commissioning would require the different players to develop new skills and approaches. The Health Service Executive would require the expertise to specify the kinds of services required, to foster their emergence, and to evaluate the offerings from different providers and monitor what is being delivered. It is also critical that quality is an integral part of what is being delivered. Arranging and buying services for people with disabilities, for example, will need to price in such things

² National Disability Authority (2011) **The Introduction of Individual Budgets as a Resource Allocation System for Disability Services in Ireland**

as quality control mechanisms, training of providers. Otherwise, services purchased at the lowest possible price may have important aspects, like quality, underprovided. Service providers would have to manage in a very different environment, with a different set of challenges. The National Disability Authority continues to work on the area of commissioning, following up on the issues raised in response to its consultation paper and seminars in this area.

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

Answer-There has been significant progress in many areas. Many of the commitments in the [National Disability Strategy](#), including commitments in the six Sectoral Plans have been delivered or are in the process of being delivered.

There have been some areas, particularly those where cross-departmental or cross-agency cooperation is required, where mainstreaming remains challenging.

The new [Housing Strategy for People with Disabilities](#) will be a major area for cross-Departmental and cross-agency co-operation. It will be important to marry the criteria for receiving a residential service that have operated within disability services, with the criteria for re-housing applied by local authorities.

To date, there has been only limited progress on delivering a comprehensive employment strategy for people with disabilities. Most vocational training for people with disabilities is contracted out to specialist training providers. FÁS employment programmes are focused on the more 'job-ready' end of the spectrum. Appropriate employment supports for people with significant disabilities will be a key area in delivering on [New Directions](#) – the review of adult day services.

Significant progress has been achieved in delivering accessible public transport. The area of door-to-door transport is fragmented between different kinds of provision operating under different authorities and regulations – taxis, Rural Transport Programme, service provider and Health Service Executive's transport, specialist disability transport such as Vantastic and ACTS, and school transport. There is scope to make better use of the existing publicly-funded and publicly-licensed transport resources, to network them better, and to examine any regulatory, fiscal or other barriers to more effective use of these scarce resources.

The establishment of revised [National Disability Strategy](#) implementation and monitoring structures can significantly contribute to resolving some of these issues.

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

Answer-Yes, more individualised supports have the potential to provide a huge opportunity for people with disabilities to access mainstream services.

However, at least initially, only a minority may be able to take advantage of this opportunity. Many people with disabilities and their families may need assistance to envisage what individualised services make possible, and to source the services they require. In this regards, consideration needs to be given to the issue that individuals will have less buying power than in a collective approach and the importance the role of Commissioning has in ensuring people get good value and good quality in the services purchased.

There will be a significant change in role for disability service providers from a role of delivering services directly, towards supporting people to access mainstream services.

Mainstream services and activities, public, private and community, may need advice and support to deliver inclusive services, and to respond to particular needs.

There are also potential risks from replacing specialist services with mainstream services. For example, in Australia, the move to mainstream housing meant that people with disabilities joined the long mainstream queue.

In the area of health care, the National Disability Authority's study of other jurisdictions found that moving to mainstream services often made it more difficult for people with disabilities to get access to specialist disability health or allied health services via mainstream primary care. In Ireland and the United States of America, the evidence is that people with disabilities living at home are less likely than those in residential services to access preventive health care. It is important to put in place plans to forestall these possibilities as an integral part of the move towards individualisation.

The National Disability Authority's work in other jurisdictions showed that mainstreaming of core elements of disability services (housing, personal support, employment supports, allied health services) creates challenges for Government Departments and agencies to ensure coordination of policy, funding and service delivery.

Question - 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?

Answer-Yes. The Health Service Executive or any successor Care Authority will need to be active in shaping the market to ensure that a choice of flexible, responsive providers develops to meet local need.

It will be a major challenge for service providers to manage fluctuating demand for their services as service users choose to move elsewhere, and to cope with rising unit costs where the number of users goes down. It will be important to build the capacity of service providers to cope with changing demands on their service and the new business model. Putting buying power in the hands of service users may encourage service providers to adapt to provide more flexible models. In the United Kingdom, for example, some providers have responded to loss of customers by being more flexible in the hours at which they deliver services.

The National Disability Authority's review of systems of disability service provision in six jurisdictions highlighted some of the practical implications for providers in making the transition to individualised supports. The National Disability Authority would be glad to undertake further work in this area, if that would be useful.

Question - 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?

Answer-Yes

Question - 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?

Answer-

Impacts on service users

The impact on service users with more complex needs and older people with disabilities should in particular be considered.

There is likely to be some degree of cross-subsidisation in the current system. If service users, with less complex needs, choose to move and take their budgets with them, this could disproportionately affect those with more complex needs who remain. This underlines the importance of tailoring the value of support packages closely to needs, using an evidence-based model.

Plans to move people to ordinary independent community settings need to be focused on service users with a spectrum of needs, to ensure that service users with more complex needs don't get left behind.

Restructuring and closing services will impact on service users. It is important that such processes are managed sensitively, and that particular attention is paid to personal relationships that are important in people's lives – relationships between service users

themselves, relationships with staff, and relationships with family and the wider community. Individual service users and their needs must be at the heart of any reconfiguration of services

Impacts on families

Some families of people with disabilities will need assistance to envisage what individualised services might make possible for their family member with a disability. In particular, it may be that some families will be asked to subscribe to a different view of risk than they have been asked to consider hitherto. The challenge of changing long-established attitudes towards risk should not be underestimated. Training and capacity building opportunities for families will be important in this regard.

The current model of wrap-around services offers families a sense of long-term security in that the needs of their adult child will be met, after the parents have died. It will be important that there is a sustainable support system in place for long-term needs, and that parents can have that reassurance.

Impacts on staff

For staff the reconfiguration of existing services will mean that a different skills mix is likely to be required. This has implications for individuals and for certain professions. Achieving a different skills mix will require the retraining of staff, and redeployment opportunities into other health or allied areas for certain professions. Many intellectual disability nurses hold dual qualifications, while there is a looming shortage of psychiatric nurses in the mental health services. The implications of the EU Directive on [Transfer of Undertakings](#) (protection of Employees) and associated legislation for the disability care services will have to be considered and planned for.

Some Irish disabilities service providers and their staff have made very significant progress in developing community based services. The National Disability Authority and others have developed an evidence base of good models of service provision in Ireland and internationally. Opportunities should be provided for staff who wish to take part in the reconfiguration process, to be exposed to different models of services through training, seminars, conferences, or training placements with progressive service providers here or overseas. The National Disability Authority would be willing to discuss with the Office of Disability and Mental Health whether it could be of assistance in this process.