

‘Promises, Commitments, and Delivery: Mid-Term Review of the Programme for Government’

DFI is calling on this Government to prioritise the following overarching goals in disability at this mid-point in its remaining term. These goals represent key indicators of the commitments made by Eamonn Gilmore and Enda Kenny to people with disabilities in their pre-election debates where disability was named as the one key social justice issue they would pursue if elected¹:

DFI Recommendations

- I. The Government to appoint a Senior Minister with dedicated responsibility for disability inclusion.**
- II. This Government to prioritise funding of disability services in line with the Taoiseach and Tánaiste’s solemn pre-election commitments to disability.**
- III. This Government to pursue the implementation of agreed measures, targets, and timelines for disability.**

- I. The Government to appoint a Senior Minister with dedicated responsibility for disability inclusion.**
 1. Disability needs to be afforded the same understanding, respect, and urgency that have been accorded to children and young people².
 2. Reform of public services is a pre-requisite for the delivery of the National Disability Strategy; there has been little evidence so far of public services working as an entity to support the inclusion of people with disabilities.

¹ “..the first area that Labour in government would address in terms of equality and in terms of giving decent supports to people would be the area of disabilities. I think as a country, we have to set that as a priority.” (Eamonn Gilmore) “That’s very laudable, I share that and I feel an absolutely priority should be the three hundred thousand people who suffer from mental illness every year.” (Enda Kenny) Extract from Final Prime Time Pre-Election Debate with Miriam O’Callaghan, February, 2011.

² The Government established a Department to focus on children and young people.

3. Disability is a societal issue that stretches across the life cycle, affecting people of all ages and their families directly and indirectly. The 'disabled' are not a category that no one else ever joins.

II. This Government to prioritise funding of disability services in line with the Taoiseach and Tánaiste's solemn pre-election commitments to disability.

1. DFI recognises the challenges for Government at this time, in the context of 5 years of recession, where not only has funding had to be severely reduced, in particular, in health services, but increased demand and demographic pressures have had to be accommodated with reduced funding.
2. Voluntary disability organisations have come under huge pressure since the recession started, with ever increasing demands on their services. The services that are so badly needed by people with disabilities should not be subject to further onslaught.
3. The balance of funding should be moved to health care services, preventative care services as well as community based services and supports provided by voluntary disability organisations, and limits should be placed on tendering and outsourcing of services. We do not believe that a market of private providers will provide the quality of life which people with disabilities should expect.
4. It is essential that any cost cutting measures are disability proofed to ensure they account for the extra cost of disability. People with disabilities have to endure a 'double-hit', when cuts are made to disability specific as well as mainstream services.

III. This Government to pursue the implementation of agreed measures, targets, and timelines for disability.

1. We would urge the Irish Government to ratify the United Nations Convention on the Rights of Persons with Disabilities as a matter of urgency so that people with disabilities can fully enjoy their rights on an equal basis with all other citizens.
2. It will be essential that the monitoring mechanisms for the National Disability Strategy Implementation Plan (NDSIP) operate effectively given the short time-frame remaining for the implementation of the plan.
3. Key pieces of legislation that have been deferred should be prioritised for implementation, including the Disability Act, 2005, the Education for Persons with

Special Educational Needs (EPSEN) Act 2004, and the Comhairle (Amendment) Bill 2004.

4. Irrespective of budgetary constraints, health service funding should be organised on a multi-annual basis to improve and facilitate proper planning. Due respect and recognition for the community and voluntary sector is required from this government – both for the disability specific and generic community organisations - who are engaged in the provision of public services. The disability community has a vital role in terms of its contribution to partnership working across the statutory, non-statutory, and private sectors, as well as in facilitating cross-departmental working.
5. This government should address the impact of the reduction in staff numbers in the public/social services that are supporting people with disabilities' access to mainstream basic services. A consequence of this depletion in human resources is that the capacity does not exist to implement government policy as outlined in policy documents, such as Future Health and therefore will result in a severely damaged social and health infrastructure, when austerity finally ends.
6. The HSE Disability Consultative Fora should be strengthened to become fora for dialogue and partnership working between the statutory and non-statutory sectors.
7. A systematic approach to collecting data on service use and demand should be prioritised, in the statutory and non-statutory health and social care sector, in support of service planning. Improved data is also needed in related areas including in housing, and transport.
8. Data needs to be gathered on the current labour market position of people with disabilities and their needs, in order to assess their distance from the labour market and what supports might be needed to address this.

PROGRAMME FOR GOVERNMENT COMMITMENTS TO PEOPLE WITH DISABILITIES

- 1. Ensure that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them.**
- 2. Facilitate people with disabilities in achieving a greater level of participation in employment, training and education.**
- 3. Publish a realistic implementation plan for the National Disability Strategy, including sectoral plans with achievable timescales and targets within available resources.**
- 4. We will ensure whole-of-government involvement and monitoring of the Strategy, in partnership with the disability sector.**
- 5. Ensure that money spent on disability services under the National Disability Strategy is clearly laid out and audited.**
- 6. Put the National Standards for Residential Services for People with Disabilities on a statutory footing and ensure that services are inspected by the Health Information and Quality Authority.**
- 7. Reform the law on mental capacity to ensure the greatest degree of autonomy for people with intellectual disabilities or suffering with mental illnesses in line with the UN Convention on the Rights of Persons with Disabilities.**
- 8. Reform the delivery of public services to bring about back office savings that will protect front line services.**
- 9. Seek to get best value for money for investment in services and to ensure that services meet the needs of users.**
- 10. Examine through a Comprehensive Spending Review all provision for people with disabilities with a view to determining how users can get the best services.**
- 11. Move a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best. Personal budgets also introduce greater transparency and efficiency in funding services.**

The pre-election commitments to people with disability made by the Taoiseach and the Tanáiste were much more robust than the subsequent commitments contained in the

Programme for Government. The same ambition was not evident there in terms of prioritising people with disabilities.

Prior to the national election in 2011, DFI called for 3 commitments that would advance the prospects for people with disabilities as full citizens of Irish society³:

1. A Programme for Government that has threaded through it actions supporting people with disabilities as equal citizens.
2. Ensuring access for people with disabilities by protecting the benefit payments and public services on which they depend.
3. Supporting self-determination of people with disabilities by building their capacity and that of their families and the voluntary disability organisations who work with them.

DFI's Review of Programme for Government

The tracking exercise below demonstrates that even with regard to the Programme for Government commitments, we have seen slow progress.

Programme for Government Commitment:

- 1. Ensure that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them.**

REDUCED DISABILITY SPECIFIC SUPPORTS

It is fair to say that the quality of life for very many people with disabilities has not been enhanced since this government's election. People's quality of life has been affected by the reduction in HSE funding impacting on people with disabilities' income, and disability services. We have seen continuous cuts in HSE funding for disability services in the order of 1.8% in 2011; 3.7% in 2012; and 1.2% in 2013. However, on an individual basis, organisations have sustained cuts in excess of these amounts from the health services.

Key supports that enable people to live in their communities have been targeted curtailing people's options to live an ordinary life with independence, choice, and control. Examples of these include the cut to the Housing Adaptation Grant of almost €60 million between 2010 and 2013⁴; the cut of 19% in the Respite Care Grant in 2013; Fuel Allowance Scheme cut

³ DFI (2011) Securing our Future: DFI's Perspective on the National Election. Available at: <http://www.disability-federation.ie/index.php?uniqueID=10272>

⁴ Budget 2014 included a commitment to allocate a portion of €200 million from the sale of the Lotto license to provide for 5,700 Housing Adaptation Grants. This is to be welcomed, but it must also be appreciated that the emphasis is on the number of grants when DFI has already stressed that people with disabilities may need costly adaptations, and may also be excluded because this is a means tested measure.

by 6 weeks in 2012, and reductions to the Household Benefits Package in 2013. These come at a time of rising costs. At the same time, DFI notes that there is a considerable level of unmet need for services, for example, 1671 people were in need of Personal Assistant services in 2011⁵ and 3,938 households where a person with a disability lives had unmet housing needs.⁶

In addition, recent mainstream health related cutbacks are damaging people's ability to live with health and well-being. These include increased prescription charges (5 times greater than what they were in 2012), the increase in the threshold of the Drugs Payment Scheme, and the rolling back of free GP care for people with certain illnesses, a cohort that has a heavy reliance on health services.

Other cutbacks are affecting people's ability to progress in the labour market, such as the reductions in funding for education supports, including the 20 per cent cut in funding for access programmes for students with disabilities in 2012.

In summary, the cumulative effect of rising costs of living, the reduced supports for community living, the reduced social welfare benefits and the new taxes and changes to existing taxes, has been the erosion of people with disabilities' income. In such a scenario, this Government cannot claim that the quality of life of people with disabilities has been enhanced since their term began.

INCOME SUPPORTS

The Programme for Government states that basic social welfare rates will be maintained. DFI does not consider that the maintenance of these basic payments at their current levels is a marker of success, when direct and indirect costs as well as inflation have been steadily increasing over the period of this recession. It is useful to remind ourselves of the situation for people with disabilities in trying to sustain an income and livelihood.

People with disabilities continue to be at risk of consistent poverty. The recent Survey on Income and Living Conditions (SILC) data demonstrated that in 2011 people not at work due to illness or disability had a consistent poverty rate of over 11 per cent, an increase of 2.3 per cent since 2009. Meanwhile, their average annual household disposable income was reduced from €31,731 in 2009 to €22,089 in 2011.⁷ A recent ESRI study found that almost one in five people living in jobless households were adults with a disability. The report also found that welfare payments were vital in lifting jobless households above the

⁵ Health Research Board (2012) Annual Report of the National Physical and Sensory Disability Database Committee 2011. Available at www.hrb.ie

⁶ Housing Agency (2013) Summary of Social Housing Assessments 2013. Key Findings. Available at: www.environ.ie

⁷ CSO (2013) Survey on Income and Living Conditions (SILC) 2011 & revised 2010 results

poverty threshold, but there has been no improvement in their living standards or levels of financial stress over the period⁸.

People with disabilities do not have the same costs of living as people without disabilities. It has long been recognised that people with disabilities and their families have extra costs in relation to their ordinary day-to-day living on items such as food, heating, clothing, and transport. People with disabilities also incur extra costs related to their health care, assistance, aids and devices. It has been estimated that the long-run cost of disability can be about one third of an average weekly income⁹.

Some examples of this include:

- A disabled person with significant mobility difficulties may have to charge a power wheelchair overnight which will significantly increase the cost of their electricity.
- Fuel costs tend to be higher for those with mobility problems because they can't heat themselves naturally from walking or moving around.

For this reason, their income is considerably reduced compared to a non-disabled person in receipt of a Jobseekers payment. Disability Allowance remains a contingency payment, on a par with Jobseekers Allowance and paid at the same rate (€188). Yet those on Jobseekers payments are expected to move back into the labour force and various activation programmes exist for that purpose. Meanwhile, many people with disabilities are likely to continue to live on the lowest of income protection supports, often for their entire adult lives.

In addition, it must be remembered that people with disabilities are subject to the same mainstream cuts as others for example, - the targeting of the Household Benefits Package in Budget 2013 and Budget 2014 - and to the extra demands being made on their income. This is a double hit, and one which is not adequately compensated for. It is arguably the case that the secondary benefits and income disregards associated with disability payments such as Disability Allowance go some way towards offsetting the extra cost of disability, but they do not form the kind of package that is needed to adequately insure against the risk of poverty and social exclusion.

In summary, people with disabilities are one of the groups most likely to be living in jobless households, and to be at risk of consistent poverty. They have extra costs related to their disability and for this reason their income is comparatively less compared to other groups in receipt of income supports. They also experience the double hit, when cuts are implemented in mainstream services, as well as disability specific services.

⁸ Watson, D., Maitre, B. & Whelan, C. (2012) Work and Poverty in Ireland: An Analysis of CSO Survey on Income and Living Conditions 2004-2010

⁹ Cullinan, J., Gannon, B., and Lyons, S. (2010) 'Estimating the Extra Cost of Living for People with Disabilities', Health Economics.

Programme for Government Commitment:

- 2. Facilitate people with disabilities in achieving a greater level of participation in employment, training and education.**

LABOUR MARKET ACTIVATION

Facilitating people to achieve greater labour market participation was promised but neither the section on equality nor jobs in the Programme for Government explicitly mentions activation or disability. DFI notes that wherever there is discussion of job creation and making a contribution to the economy in official government fora, there is invariably a 'blind spot' when it comes to participation by people with disabilities. The message is still being delivered that people with disabilities are unlikely to be economically productive and more likely to be economically dependent as well as a perception that segregated provision is sufficient.

This thinking permeates into policy planning, and decision making in the areas of employment and labour market activation. Evidence for this is to be found in a number of areas, not least the fact that people on disability payments' access to activation measures is blocked where a measure is only open to those in receipt of a jobseekers' payment. Eligibility for the Tús Scheme remains closed to recipients of disability related payments and the Springboard Programme had previously been closed to this cohort. People in receipt of Disability Allowance can now access the JobBridge Internship Scheme, but only as a result of the disability movement intervening to advocate for the inclusion of people on Disability Allowance. This scheme though is still not open to people on Blind Pension. The labour market education and training fund, Momentum was launched in December 2012. It provides a range of relevant education & training interventions targeting up to 6,500 long-term unemployed including young people¹⁰. This initiative was only open to those on jobseekers' payments, i.e. those on the live register. As a follow on to this programme, approximately 2,000 training places are being ring-fenced for under 25s who are out of work in 2014. It is uncertain at this stage whether these programmes will be open to people in receipt of disability payments.

While the increased spending on the roll-out of Intreo offices is welcomed, the service is aimed at jobseekers and those on the live register. The Intreo service that intends to provide a 'one-stop shop' for all employment and income supports underlines the divisions between those in the category of being available for work, and those in the category, of being unable to work due to illness and disability. It is true that for a certain portion of people with disabilities, full-time work will not be an option for them, but there, are many more, whose will and preference it is to be in work, where the necessary supports are

¹⁰ http://ec.europa.eu/europe2020/pdf/nd/prgreg2013_ireland_en.pdf

provided as needed¹¹ (e.g. flexible working arrangements, adaptations and accessibility measures). Intreo must take into consideration the needs of people with disabilities who are not on a jobseekers payment, but who are seeking work.

Even during the height of the boom, people with disabilities were under-represented in the labour market with an employment rate of 33% for people with disability or health problems, which was among the lowest in the OECD¹². Census 2011 meanwhile showed that 20% of people with disabilities aged 15 or over were at work. Strong work disincentives for those on welfare payments continue to present challenges, i.e. the loss of secondary benefits upon moving into work, especially the medical card, and mobility allowance. A recent example of this was the measure introduced in Budget 2014, which will mean that a person with a disability who is returning to work will not be allowed to keep their medical card for 3 years. They will be given a GP visit only card instead, which will not cover the additional and costly supports a person with a disability may need. People with disabilities need much improved and secure pathways to participation in employment or education, avoiding the benefits trap.

It is notable that Ireland's update to the National Reform Programme 2013 contains no update on the situation for people with disabilities in relation to their activation. It only rightly points out that they are one of the cohorts with lower than average participation rates and are most at risk of losing contact with the labour market¹³.

The focus is on removing people from the Live Register, thus people with disabilities continue to get left behind in new measures targeting the unemployed. A Comprehensive Employment Strategy for People with Disabilities has yet to be finalised and we still do not know which Department will have responsibility for the implementation of the Strategy.

In summary, DFI considers that little has been achieved in this government's term to progress the commitment of facilitating people with disabilities in achieving a greater level of participation in education, training, and employment. There has been insufficient planning and targeting of resources to support those who are able and willing to participate in activation measures.

EDUCATION

DFI welcomed the commitment to producing an implementation plan for the EPSEN Act 2004 in the Programme for Government as well as the recognition of the importance of early intervention. However, the Implementation Plan does not contain any commitment to commencing all sections of the EPSEN Act 2004. The Special Education Appeals Board has yet to be established and assessments of need and Individual Education Plans have

¹¹ Over a third (37%) of people with disabilities have said that they wanted to work if the circumstances were right and for young people this actually increased to two thirds of those sampled in the National Disability Survey.

¹² OECD (2010) Sickness, Disability and Work: Breaking the Barriers.

<http://www.oecd.org/ireland/46461490.pdf>

¹³ http://ec.europa.eu/europe2020/pdf/nd/prgprep2013_ireland_en.pdf

not been brought into force across the board. While implementation is being coordinated by the National Council for Special Education (NCSE) there remains no date specified for the execution of these elements of the act¹⁴.

The cut in the budget for the National Council for Special Education (NCSE) by €2.3 million in 2011, the capping in the number of Special Needs Assistants in 2011, and the restriction in the number of National Educational Psychological Service (NEPS) psychologists to 178 in 2011 occurs at a time when the demand for special educational resources is increasing. DFI welcomed the decision to maintain funding for special education at €1.3 billion in 2014 and to the commitment to recruit 455 extra Resource Teachers for children with special education needs.

Recent research has also demonstrated that access to resource hours and special needs assistants is inequitable across different socio-economic areas, with 'wealthy' areas receiving more special education teaching¹⁵. The reason for this is that parents from lower socio-economic backgrounds are often unable to afford access to an Educational Psychologist to have a formal assessment of their child completed.

DFI welcomes the Education/Health Cross Sectoral Group which includes representation from the Department of Education and Skills, the Department of Health and Children and the HSE at national level and through interaction with the HSE and their service providers at local level.

Supports for educational participation have also been restricted over the past couple of years. Funding for access programmes for students with disabilities was cut by 20 per cent in universities in 2012 impacting on supports such as assistive technology, learning support, academic assistance and campus accommodation. It is worth emphasising that this fund is not available to part-time students or students in further education. In addition, the increase in registration fees for third level education, announced in Budget 2014 will hit students with disabilities even harder who already incur extra costs related to their disability.

Other measures targeted included the Cost of Education Allowance (€300) payable to Back to Education Allowance participants, which was discontinued for new and existing participants in Budget 2013 as well as the cuts in the rate of Back to Education Allowance for new participants (from January, 2013).

In summary, over the past ten years and more, people with disabilities' expectations have been changing, and it is rightfully the norm now to expect children with disabilities to attend mainstream schools. Increasing demographic pressures and expectations must be incorporated into Government's educational planning going into the future.

¹⁴ <http://www.citizensinformation.ie/en/>

¹⁵ Mary Minihan. Aug 5th 2013 'Children in wealthy areas get more special education teaching' in The Irish Times.

Programme for Government Commitment:

- 3. Publish a realistic implementation plan for the National Disability Strategy, including sectoral plans with achievable timescales and targets within available resources.**
- 4. We will ensure whole-of-government involvement and monitoring of the Strategy, in partnership with the disability sector.**
- 5. Ensure that money spent on disability services under the National Disability Strategy is clearly laid out and audited.**

NATIONAL DISABILITY STRATEGY

The first meeting of the National Disability Strategy Implementation Group (NDSIG) took place on the 30th November 2011 where it was announced that an Implementation Plan for the NDS would be put in place within six months. This deadline was not achieved, and in addition, there were a number of further delays. The NDS Implementation Plan (NDSIP) was finally published at the end of July, 2013.

While DFI welcomed the re-commitment to the high level goals of people with disabilities being treated as equal citizens, independence and choice, participation, and maximising potential, overall, there are a number of areas where the Plan falls short. It does not include many of the priority actions which DFI sought since the start of the drafting process for the NDSIP. In addition, many of the actions committed to by departments are general and vague, and many have inadequate timelines.

There is no priority given to the important role played by existing community services and supports funded through the HSE, and other Departments, that enable people's access and participation in life in the community. Equally, there is no mention of supports such as Personal Assistance, a vital support in independent living for many people, nor is there adequate attention for the unmet housing need for people with disabilities already living in the community.

DFI's key concern at this time is that we are not seeing the ambition set out by the Taoiseach and the Tánaiste during their pre-election campaign necessary for the delivery of these high level goals. Underpinning this whole process is public service reform which is crucial for the successful implementation of the National Disability Strategy. Fulfilling the commitment made in the National Disability Strategy Implementation Plan to cross-departmental and cross agency working will require new approaches and in many cases, a cultural shift in ways of working. The non-statutory sector plays a key role in supporting ways of working. The public service reform programme is the ideal mechanism to move

forward on the agenda of inclusion of people with disabilities and on the commitments contained in the National Disability Strategy.

In summary, DFI considers that the Plan is not comprehensive, and it lacks a true whole of government approach, as evidenced already in a lack of cohesion across departments in the development of the Plan. Equally, there is a conflict between the actions stated in the NDSIP, and the reality of Government decisions that have been taken over the past number of years.

LOCAL GOVERNMENT REFORM

The Programme for Government committed to a fundamental reorganisation of local governance structures to allow for devolution of much greater decision-making to local people.

Since the National Disability Strategy (NDS) was announced in 2005, DFI has drawn attention to the evolving links between the local implementation of the NDS and local government decision-making structures and the impact these have on the lives of people with disabilities.

DFI welcomes the publication of “Putting People First” in October 2012 by the Minister for Environment, Community and Local Government, which sets out the government’s strategy for the reform of local government. Among many other reforms a new local structure, the Local Community Development Committees (LCDCs) will be established in each local authority area, which will have oversight and administration of many local development funding streams.

DFI is concerned that there must be adequate representation of people with disabilities on these local structures, to ensure that a true partnership approach can support achieving the goal of mainstreaming in the National Disability Strategy at a local level.

Programme for Government Commitment:

- 6. Put the National Standards for Residential Services for People with Disabilities on a statutory footing and ensure that services are inspected by the Health Information and Quality Authority.**

RESIDENTIAL SERVICES

The National Standards for Residential Services for People with Disabilities have been a priority of this Government and that is to be welcomed. While we recognise the importance of ensuring that existing residential services are safe and effective, it needs to be

remembered at all times, that the goal should be to provide people with choice as to where and how they live their lives.

DFI would like to see the four high level goals of the NDSIP, as the overarching framework for the implementation of the standards for residential services where people with disabilities are treated as equal citizens, are supported to live the life they choose, can live ordinary lives in ordinary places, participate in the life of the community, and are enabled to reach their potential. Government policy is to support community living for people with disabilities, yet each year we are seeing a steady erosion of the very supports that enable this.

An example of the challenges with regard to residential services is the numbers of younger people with disabilities living in nursing homes. One study demonstrated that there was a total of 42 people with disabilities aged under 65 years (ranging from 27 up to 65) living in nine nursing homes in the Bray/Greystones area. They had lived in the nursing homes for various lengths of time from 2 months up to 20 years without access to the social and rehabilitative supports they may have needed. HIQA regulation of nursing homes does not cover a review of the placement, to check and see how the person is progressing, or whether they are maintaining or losing skills as well as the on-going suitability of the placement and supports¹⁶. More attention to this issue is required, where on the one hand progress is being made in moving a cohort of people with disabilities out of congregated settings, while on the other hand, people with disabilities are being moved in to nursing homes.

Programme for Government Commitment:

- 7. Reform the law on mental capacity to ensure the greatest degree of autonomy for people with intellectual disabilities or suffering with mental illnesses in line with the UN Convention on the Rights of Persons with Disabilities.**

LEGAL CAPACITY

DFI welcomes the publication of the Assisted Decision Making (Capacity) Bill 2013, in July of this year, five years after the Scheme of the Mental Capacity Bill 2008 was published. We view the Bill as progress in allowing people with acquired brain injury, mental health difficulties, intellectual disabilities and older people with dementia, and neurological conditions make fundamental decisions about their life, for example, in relation to their finances, where they choose to live, or about their medical treatment, and to have those decisions respected in law.

¹⁶ Bray Area Partnership & the Citizen's Information Board (2013) Old too Soon – Younger People with Disabilities Living in Nursing Homes in the Bray & Greystones areas of Co. Wicklow.

The Bill contains some positive support measures, such as the opportunity for individuals to make legally binding agreements with others to assist and support them in making their own decisions. Under the guiding principles, the ‘will and preferences’ of the person making a decision must be given effect, in so far as is reasonably practicable. A coalition of civil society organisations in the fields of disability, mental health, and ageing has made a number of recommendations on amendments that would strengthen the Bill.¹⁷ DFI concurs with these amendments, and would like to highlight in particular:

- the importance of explicitly recognising legal capacity as an individual right,
- according the highest respect for the will and preferences of an individual in decision-making agreements, and
- explicit recognition of the role of independent advocacy including the National Advocacy Services, and other specialised independent voluntary and community advocacy services (providing peer advocacy, citizen advocacy, self-advocacy and other forms of advocacy) in the Bill.

Programme for Government Commitment:

- 8. Reform the delivery of public services to bring about back office savings that will protect front line services.**
- 9. Seek to get best value for money for investment in services and to ensure that services meet the needs of users.**
- 10. Examine through a Comprehensive Spending Review all provision for people with disabilities with a view to determining how users can get the best services.**
- 11. Move a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best. Personal budgets also introduce greater transparency and efficiency in funding services.**

PUBLIC SERVICES AND SUPPORTS

Funding commitments were scarce in the Programme for Government with the emphasis being placed on making savings and achieving efficiencies, and not enough on planning for and addressing people’s needs. At the same time, over-arching commitments to protecting the vulnerable, and prioritising social justice were made without robust implementation mechanisms. While it is recognised that public resources are constrained at present, the gap between public service provision and what people with disabilities should experience as full citizens, must be recognised.

¹⁷ Submission to the Department of Justice and Equality: Textual Amendments to Assisted-Decision Making (Capacity) Bill, 5 November 2013

The Programme for Government states that the spending review “will move a proportion of public spending to a personal budget model”. There has been slow progress towards achieving this objective, and at the same time a steady chipping away at the kinds of flexible supports that support choice, autonomy and independent living, for example, Personal Assistance, Mobility Allowance/Motorised Transport Grant, the Long-Term Illness Scheme, and the Housing Adaptation Grant. Equally there has been little recognition of community services and supports focusing on positive outcomes for people with disabilities including supporting them to live a quality life in their community. The wider role of voluntary disability services – as more than traditional service providers - was not fully appreciated in the Programme for Government. The Value for Money Review noted the following:

“It should, however, be noted that some agencies (particularly those serving people with physical disabilities) have developed from a community base, with the aim of promoting and protecting client choice, control and independence. These agencies already operate a client-focused model of service and provide examples of good practice, which can be used to inform decision-making in the wider disability sector (DoH: 3).”

A client focused model of service costs relatively little: an analysis of the data in the Value for Money Review demonstrated that over half of the voluntary disability organisations (124) only received 2.2% (€28m) of the overall Disability Services Programme budget in 2009. The lack of recognition and valuing of these kinds of services is reflected in recent policy documents published since the Programme for Government, (for example, Value for Money and Policy Review of Disability Services in Ireland (2012); Future Health (2012)).

HEALTH

People with disabilities need a combination of disability-specific services and access to mainstream health services. An effective mix depends on the development of the right infrastructure and culture across the health system, including primary care teams, acute and chronic care services. In this regard, DFI was disappointed that the first phase of the roll out of free GP care, i.e. the delivery of free GP care for the 70,000 people on the long term illness scheme was postponed¹⁸. Minister Alex White commented that it was difficult to ‘shoehorn a free GP system based on illness into a system under the current medical card scheme that was based on financial need.’

It is recognised that there is a clear medical need for at least 70,000 people. However, in reality, this figure is more likely to be higher if people whose illness is included in the definition/eligibility criteria for the long-term illness scheme. If the intention is to move to a single-tier health system where access is based on need and not ability to pay, and to remove the inequalities between public and private patients, it is right that people with

¹⁸ It took nearly two and a half years for the Government to identify the extent of the legal problems with the free GP scheme. Minister Alex White said that significant problems had arisen in terms of granting free GP care to people with chronic illness. He said it was ‘a big ask’ to shoehorn a free GP system based on illness into a system under the current medical card scheme, that was based on financial need’.

www.irishhealth.com, 11/05/2013

disabilities and with chronic conditions are prioritised from the outset in this transformation plan.

Moving to care in the community as envisaged in Future Health¹⁹, and a system where money follows the patient is no doubt a fundamental change, in the way health services will be delivered. A second key plank of this health policy is the need to increase the number of GPs and primary care centre staff, including therapy services to deliver on this commitment. Primary care services often do not offer the range of services or supports required by someone with for example, a neurological condition.

However, there have been serious delays in the delivery of extra primary care staff in 2013. In addition, withdrawal of €150 million from the budget for the delivery of GP services, along with recent cuts to GP fees for delivering services, has impacted on GPs willingness to do any work that is not covered by the terms of the GMS (medical card) contract. This includes work relating to primary care teams, community intervention teams and clinical care programmes (chronic disease)²⁰.

Another example, of where stated policy diverges from practice, is in relation to the withdrawal of discretionary medical cards. Recent data show that the number of discretionary medical cards fell from 80,524 at the start of 2011 to 63,126 at the end of 2012, and in the first seven months of 2013 there was a further reduction of 8,142 such cards to 54,984²¹. A discretionary medical card is for people who are over the income limit but have a chronic long-term illness necessitating high medication costs and visits to doctors. The HSE must consider if refusing eligibility would result in undue hardship for that person and his/her dependents, thus the discretionary nature of this support.

The discretionary medical card covers the extra costs faced by the person and his/her children that are directly related to their disability, which in a sense equalises the playing field for that person or child with a disability. DFI considers that targeting those with a strong medical need, is unjust, damages the existing infrastructure, does not provide a pathway to a transformed health system and ultimately erodes the hope that people with disabilities so badly need at this time. In this regard, DFI welcomes the commitment in the National Service Plan 2014 not to proceed with the savings sought of €113m in the medical card probity.

Fine Gael's 2011 Election manifesto included the prioritisation of the development of neurological services and implementation of the national rehabilitation strategy. DFI welcomes progress achieved in this regard in that an implementation group has been set up and a draft implementation plan is expected in early 2014.

¹⁹ Department of Health (2012) Future Health: A Strategic Framework for Reform of the Health Service 2012 – 2015.

²⁰ Irish Times, 'GPs to withdraw from primary care teams', 12/7/2013

²¹ Dail Debates, Private Members Motion (Deputy Billy Kelleher) 8th October 2013. Available at <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2013100800043>

DFI is also concerned about the drive towards a strategic commissioning model for disability services this government seems to have wholeheartedly embraced. Our initial concerns centre on issues related to:

- **Quality:** Will contracts be awarded to the organisation that submits the best bid on paper, or to the organisation that can provide the best service to people with support needs?
- **Impact:** What will be the potential impact on outcomes for people with disabilities in this new system, for example, interruption to service continuity, distress for people with disabilities and their families, deterioration in workforce terms and conditions?
- **Practice:** What about the skills and abilities of the Commissioning Agency to conduct procurement exercises?
- **Introduction of Further Cuts:** Will the procurement exercise be used to even further cut funding for disability services?
- **Workforce Terms and Conditions:** In many voluntary disability organisations, workforce costs in the provision of community services and supports amount to approximately 85 per cent of all service costs. Will public procurement put undue pressure on pay and conditions, leading to low wage levels, and ultimately, an inability to deliver these services and supports?

The government's track record in the management of the health areas does not inspire confidence and is a cause for serious concern for people with disabilities for their remaining term in government.

Conclusion

In conclusion, DFI recognises that this review is highly critical, but it is also meant to be constructive and to inform Government as it prioritises and shapes its remaining term in Government. DFI acknowledges that exiting the bailout is a major achievement. DFI's role is to insure that people with disabilities are as much a part of Ireland's future as every other citizen.

DFI's judgement is that this Government is not facing the challenge of inclusion for people with disabilities as an integral part of Ireland's social and economic progress and furthermore, is not using the public service reform programme to advance this agenda. This agenda – the inclusion of people with disabilities - was well set out by the Taoiseach and Tánaiste, in their pre-election statements and which is also underlined by their commitment to ratify the United Nations Convention on the Rights of People with Disabilities.

We are seeking an investment in sustainable social outcomes so that people, as well as the economy, have opportunities for recovery and growth. To achieve this, we are calling for the implementation of the following recommendations:

1. The Government to appoint a Senior Minister with dedicated responsibility for disability inclusion.
2. This Government to prioritise funding of disability services in line with the Taoiseach and Tánaiste's solemn pre-election commitments to disability.
3. This Government to pursue the implementation of agreed measures, targets, and timelines for disability.



**Representing the interests and expectations of people with disabilities to be fully included
Comprising organisations that represent and support people with disabilities**

The Disability Federation of Ireland (DFI) represents the interests and the expectations of people with disabilities to be fully included in Irish society. It comprises organisations that represent and support people with disabilities and disabling conditions.

The vision of DFI is that Irish society is fully inclusive of people with disabilities and disabling conditions so that they can exercise their full civil, economic, social and human rights and that they are enabled to reach their full potential in life. DFI's mission is to act as an advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of their lives.

There are over 130 organisations within membership, or as associates, of DFI. DFI also works with a growing number of organisations and groups around the country that have a significant disability interest, mainly from the statutory and voluntary sectors. DFI provides:

- Information
- Training and Support
- Networking
- Advocacy and Representation
- Research and Policy Development / Implementation
- Organisation and Management Development

DFI works on the basis that disability is a societal issue and so works with Government, and across the social and economic strands and interests of society.

For further information go to www.disability-federation.ie

Disability Federation of Ireland, Fumbally Court, Fumbally Lane, Dublin 8
Tel: 01-4547978, Fax: 01-4547981

Email: info@disability-federation.ie Web: www.disability-federation.ie

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