

21st December 2015

These comments have been developed, in collaboration with Mental Health Reform's Grassroots Forum to inform phase 2 of the Department's consultation on the NDSIP. Mental Health Reform recommends that the following high level objectives [under each of the proposed key themes] should be included in the revised NDSIP. A rationale is provided under each of the proposed high level objectives for its inclusion.

Education

Recommended objective: Adults with disabilities who are not in work are supported to participate in mainstream training and education

According to international evidence approximately half of participants in supported employment programmes with mental health disabilities do not find competitive employment. This leaves a significant group who require other rehabilitative and vocational support in order to ensure that they do not become socially excluded.

Mental Health Reform recommends that educational institutions should give people with mental health difficulties credit for their lived experience for the purposes of both applications and within course programmes. People should also be supported to complete education and training courses in stages, taking account of the particular challenges some people with mental health difficulties may experience.

Recommended objective: Children and young people are provided with the environment and education to prevent disability

The publication of the national guidelines on promoting positive mental health and suicide prevention is positive, ¹ ² as is the *Connecting for Life* strategy on suicide prevention. The national guidelines recommend a 'whole school approach' to mental health promotion in which all stakeholders involved in the school can play a role. However, the Children's Mental Health Coalition (CMHC) has called for a clear implementation plan to ensure the guidelines translate into action. This should be complemented by the necessary training, resources and support for schools.

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¹ Department of Education and Skills (2013) Well- being in Post Primary Schools: Guidelines for Mental Health Promotion and Skills (2015) Well- being in Primary Schools: Guidelines for Mental Health Promotion, Dublin: Department of Education and Skills (2015) Well- being in Primary Schools: Guidelines for Mental Health Promotion, Dublin: Department of Education and Skills.

Employment

The objective "it pays to take a job" should be replaced by:

"The social welfare system supports people to take up employment"

Mental Health Reform has previously identified the importance of a flexible benefits system in order to facilitate opportunities for people with a mental health difficulty to try work, fall out of work and re-enter the work force numerous times, without fear of losing income support. Mental health difficulties are often episodic and it can take years before some individuals settle into how to manage their condition and maintain stability. Anxiety is itself a significant feature of many mental health conditions and can also exacerbate underlying mental health conditions. The threat of losing benefits can cause anxiety and deter people with a mental health difficulty from seeking work.

The current Partial Capacity Benefit scheme often discourages people with a mental health disability from taking up work because they must undergo a review of work capacity that can result in removal of their existing disability benefit. Mental Health Reform considers that the risk of losing benefits to take up employment should be removed for people with mental health disabilities in order to support their recovery and encourage their participation in the labour market.

The benefits system should ensure that individuals on benefits can automatically revert to benefits if they lose their job, with an appropriate income support assessment to follow after reinstatement of benefits. It is also important to note that many individuals with a mental health disability are deterred from taking up employment for fear of losing their medical card. Mental Health Reform has previously advocated that it will be important to provide people with long-term mental health conditions the security of a medical card, in order to help prevent relapse and support their ability to enter into and sustain employment.

In order for the social welfare system to adequately support people into employment, it is important that there is an increased awareness of the benefits system among members of the public.

The objective on employment of people with disabilities should specify also people with a mental health difficulty

According to Census 2011 data only 43.8% of the working age population of people with a mental health disability are in the labour force compared to 61.9% of the overall population over age 15.³ Furthermore, people with a mental health disability are nine times more likely to be out of the labour force than those of working age without a disability, the highest rate for any disability group in Ireland.⁴ Yet, half of adults with a mental health disability who are not at work have said that they would be interested in starting employment if the circumstances were right.⁵

Widespread evidence shows that it is important to provide employment supports early for people who experience a mental health difficulty in order to prevent long-term disablement and absence from the workplace. It is therefore important that the National Disability Strategy address

³ CSO Census Profile 8 – Our Bill of Health – Health, Disability and Carers in Ireland.

⁴ Watson, D., Kingston, G. and McGinnity, F. (2012) Disability in the Irish Labour Market: Evidence from the QNHS Equality Module, Dublin: Equality Authority/Economic and Social Research Institute, p.19.

prevention of unemployment among people with a mental health difficulty by promoting early intervention with people with a mental health difficulty to support them to return to work.

Recommended objective: People with disabilities, including individuals with mental health difficulties are supported in accessing and maintaining employment.

The current system of supports for people with mental health disabilities has not been successful in facilitating access to employment. Challenges for people with a mental health difficulty in this area include ineffective links between mental health and supported employment services, concerns around the flexibility of welfare benefits, as well as the prejudice and discrimination surrounding mental health difficulties in work environments. Mental Health Reform has previously advocated that the Department of Social Protection, the Department of Health and their agencies should work together to put in place the evidence-based approach to supported employment in order to meet the needs of people with mental health disabilities.

Health and well-being

The proposed first objective on health and wellbeing should be replaced by:

"The disparity between the physical and mental health outcomes of people with disabilities and those without a disability is reduced".

People with a severe mental health disability die, on average, 25 years earlier than those without a mental health disability. This disturbing statistic reflects many factors, particularly poor physical health care provided to people with a mental health disability. This situation points to the need for much better integration between physical and mental health services.

Recommended objective: Children at risk of developing a disability would receive early intervention support.

In terms of early intervention, it is now widely accepted that the foundation for healthy, psychological, social and emotional health across the life span is developed in infancy and early childhood. Early intervention needs to include a response which places the social and emotional health and well-being of infants and toddlers on par with that of their physical health. Despite a number of existing early intervention programmes which have been funded by Government there is a need for investment in the development of early intervention services which specifically target the mental health needs of infants and young children. Such programmes should be established on a national basis. Capacity should also be developed within perinatal and infant health services to enable professionals to support the social and emotional development of children in their early years.

Person centred disability services

The theme "person centred disability services" should be replaced by "person-centred disability and mental health services".

Given that disability and mental health services are provided through two separate divisions within the HSE, it is important to acknowledge that person centered services should underpin both disability and mental health services.

Recommended objective: All individuals with mental health difficulties can avail of 'recovery orientated' mental health services.

It is vital that the 'recovery' principle that underpins *A Vision for Change* is incorporated into the NDSIP. This principle recognises that services should:

- operate from a hopeful orientation that supports recovery
- listen to and work in partnership with people who use services
- offer choice and the opportunity for individuals to exercise their autonomy, and
- support the social inclusion of people with a disability

The recovery principle is further endorsed by the Mental Health Commission in its Quality Framework for mental health services and in its report on a recovery approach within Irish mental health services.

Recommended objective: People with disabilities are provided with opportunities to build positive and sustained relationships with mental health professionals providing their care.

Mental Health Reform's Grassroots Forum has reported that there is a lack of consistency with respect to staff working with individuals with mental health difficulties. Many individuals feel that they see numerous professionals in very short timeframes. This has an adverse impact on the individual in that they have to continually repeat sensitive information to a number of different professionals, many of whom they have no relationship with, or have not seen before. This is a problem particularly in relation to psychiatrists, wherein under the current system a long-term mental health service user is usually required to see a different psychiatrist every six months, constantly disrupting the continuity of their care relationship. It is also fundamentally disrespectful of long-term mental health service users to have a system that operates on the basis that they must see a different psychiatric clinician every six months.

Housing

Recommended objective: Government should ensure that there is an adequate supply of housing for people with disabilities

The Strategic Plan for Housing Persons with Disabilities recommends that local authorities ensure that a proportion of social housing is allocated to people with mental health difficulties in each local area. Given that the vast bulk of mental health care is delivered in the community, there will be a small but regular flow of individuals with a mental health disability who will require social housing

support. HSE guidance on addressing the housing needs of people with mental health difficulties states that:

They [mental health services and local authorities] need to engage in estimating and planning for the provision of an adequate stock of suitable living accommodation for mental health service users who have special needs in relation to their living environment and the development of mechanisms to ensure equity of access for people with a mental illness to the housing allocations process. (HSE (2012) *Addressing the Housing Needs of People using Mental Health Services: A guidance paper*, page 15).

A study conducted in the Tallaght mental health services found that 98% of the long-stay/delayed discharge patients had a housing-related need. In order to prevent inappropriate and costly long-term stays in acute mental health units, it is vital that people who are in acute units and who have a housing need can access social housing quickly. This requires that the planning mechanisms used by local authorities to estimate current and future housing need take account of the cohort of individuals with severe mental health difficulties who will need social housing support.

Recommended objective: People with disabilities should be supported to secure appropriate housing

Mental Health Reform has previously advocated for a dedicated funding stream to provide medium and long-term tenancy sustainment (also called 'visiting') support to individuals with long-term mental health difficulties. The Implementation Framework for the National Housing Strategy for People with Disabilities recognises that the HSE will be required to continue to provide health and personal social services for people transitioning from mental health service accommodation.⁶

However, in addition to mental health support, some people with a mental health disability will need visiting support to help them sustain their housing situation.

The Australian Human Rights and Equal Opportunities Commission found that one of the biggest obstacles in the lives of people with mental health difficulties is the absence of adequate, affordable and secure accommodation. This need is underscored in the HSE's guidance paper on addressing the housing needs of mental health service users. The HSE guidance paper illustrates a range of housing and housing support models currently in operation which emphasise and underpin the requirement for tenancy sustainment support for those transitioning from mental health service accommodation. It is important that a dedicated funding stream for visiting support is provided so that the Government's policy of deinstitutionalization is not hindered by a gap in housing support in the community.

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⁶ 27 Department of Environment, Community and Local Government (2012) National Housing Strategy for People with a Disability 2011-2016: National Implementation Framework, p.11.

The objective "people with disabilities are supported to live independently in ordinary homes in the community" should be replaced by:

"People with disabilities are supported to live independently in sustainable communities".

It is important that people with disabilities are provided with appropriate housing in order to prevent mental health difficulties and to support individuals' recovery. Feedback from Mental Health Reform's Homeless Sector Advisory Group highlights that often people with mental health difficulties are placed in inappropriate accommodation which can exacerbate existing mental health difficulties. Mental Health Reform's Grassroots Forum has recommended that people with mental health difficulties be housed in communities with infrastructure that supports improved living standards, including good transport links and community supports for the individuals' recovery. Members of the Forum expressed concern that placing people with mental health difficulties in areas where there is little service provision may have an adverse effect on the person's mental health and recovery.

Recommended objective: People with disabilities are prevented from becoming homeless

There is a high prevalence of housing need among people with mental health disabilities as well as an increased risk of homelessness among this group of individuals. The Housing Agency's Assessment report, 2013 identified that 1,034 households in Ireland has a household member where the main need for social housing is as a result of having a mental health disability. Between 2012 and 2013 an audit was carried out in an acute mental health unit in Tallaght Hospital in relation to housing need. The study found that 98% of long stay patients/delayed discharge inpatients had accommodation related needs and there was an individual discharged into homeless services every 9.4 days. People with mental health difficulties are also experiencing significant social exclusion in terms of housing due to rent supplement and housing assistance payment caps. Current rent supplement caps are out of line with market rates and rental tenants are competing for limited housing stock. The housing crisis is a major negative factor in individuals' ability to recover from mental or emotional distress, since secure housing is a vital basis for mental health.

Equality

The objective of 'being treated with equality and respect' should encompass improving public attitudes towards people with disabilities.

In the National Disability Authority's Attitudes Survey 2011, respondents reported relatively higher comfort levels with having a work colleague with a physical, hearing or vision disability compared with a colleague with a mental health disability. Similarly, respondents reported low levels of comfort with people with mental health difficulties living in their community, in comparison to other types of disabilities.⁸

⁷ Housing Agency (2013) Summary of Social Housing Assessments 2013: Key Findings, p. 10.

⁸ National Disability Authority (2011) Public Attitudes to Disability in 2011 available at https://www.ucd.ie/t4cms/ Public_Attitudes_to_Disability_in_Irelandfinal%20Report%20 2011.pdf.

The See Change Attitudes Survey 2012 showed some improvement in attitudes towards people with mental health difficulties generally since 2010, though "attitudes towards people with a diagnosis of schizophrenia still lag behind".⁹

One of the strongest concerns voiced by service users to the Expert Group (in developing AVFC) in 2006 was the issue of stigma and discrimination faced by people with mental health difficulties. In recent years the See Change stigma reduction partnership has been an important means of stimulating public discussion about mental health and has begun to have an impact in reducing negative attitudes towards people with mental health difficulties. While there has been some improvement in attitudes around mental health, attitudes towards people with severe mental health difficulties do not appear to have improved, leading to their continued social exclusion and hindering their recovery.

Attitudinal and behavioural change is a slow, long-term process that requires sustained support by Government. It is important that the next NDSIP also acknowledges the important role the community has to play in supporting people's recovery from mental health difficulties.

Recommended objective: People with disabilities are not discriminated against in employment or the provision of goods and services

The Employment Equality Acts 1998-2008 expressly prohibit discrimination on the grounds of a mental health disability. However in a study by DCU 36% of participants reported having experienced unfair treatment in finding a job and 43% in keeping a job.¹⁰ Amnesty International Ireland concluded that it is likely discrimination by employers against people with a mental health disability is occurring in Ireland.¹¹

Recommended objective: Health services should be culturally appropriate and accessible to people from the deaf community.

Among members of the deaf community, approximately 40-50% of individuals are likely to experience mental health difficulties at some time in their lives.³ Despite the high prevalence of mental health difficulties among this group there are significant gaps in mental health services for people who are deaf. Such difficulties include a lack of appropriate communication mechanisms between mental health professionals and people who are deaf, including interpretation facilities.

Recommended objective: People with disabilities do not end up unnecessarily in the criminal justice system.

Nursing, Dublin City University) (2010), *Hear my voice: The experience of discrimination by people with mental health problems*, Dublin: Amnesty

International Ireland.

⁹ See Change (2012) Irish attitudes towards mental health available at http://www.seechange.ie/wpcontent/themes/seechange/images/stories/pdf/See_Change_Research_2012_Irish_attitudes_towards_mentl_health_problems.pdf

¹⁰ MacGabhann, L, Lakeman, R, McGowan, P, Parkinson, M., Redmond, M, Sibitz, I, Stevenson, C, Walsh, J, (School of

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¹¹ Amnesty International Ireland (2010) *Hear my voice: challenging mental health prejudice and discrimination,* Dublin: Amnesty International Ireland, p.49.

It is widely recognized that people with a disability, particularly those with a mental health or intellectual disability, may end up coming to the attention of the criminal justice system when their support needs are not adequately met. The National Disability Strategy should set out a specific objective to reduce the extent to which people with a disability end up in the criminal justice system by, for example, ensuring the widespread availability of a diversion system as early as possible.

Recommended objective: People with disabilities are provided with the necessary supports to make decisions.

There is currently no right to advocacy under the Mental Health Act, 2001 and the statutory advocacy service envisaged in the Citizens Information Act, 2007 has not been implemented. The National Advocacy Service, established under the Citizen's Information Board provides advocacy services to people with disabilities with complex needs living in the community, and the Irish Advocacy Network provides advocacy supports to individuals in inpatient services; however, these services are provided on an administrative basis and fall far short of meeting the need for advocacy supports. There is a need for the right to advocacy to be defined within the legal framework on mental health. To complement this right, the Government should ensure the establishment of a range of advocacy services through allocated funding. There is also no national advocacy service for children and young people using public mental health services in Ireland.

The supports provided for under the Assisted Decision Making Bill should be resourced as a matter of priority, to ensure that people with disabilities can be empowered to make their own decisions.

Recommended objective: Advance healthcare directives should apply equally to people with mental health difficulties.

Currently, under the capacity legislation, people who are involuntarily detained under Part 4 of the Mental Health Act are excluded from legally binding advance directives.

Advance directives are a way for people to articulate their will and preference for decisions at a later date in which their views may become unclear or unknown. Too often, mental health issues are seen as 'separate and different' and the same rights protections are not extended to mental health service users as others.

The use of differential standards for treatment decisions during involuntary detention perpetuates stigma and limits the use of AHDs in mental health settings. Stigma and discrimination have been identified as the greatest barriers to recovery.

Recommended objective: Health services provide care on an equal basis to people with mental health difficulties.

In its 2013 report, the Royal College of Psychiatrists, UK reported on the continuing lack of parity between mental and physical health.¹² This was further reflected in the UK Parliament's research briefing on parity of esteem for mental health.¹³ While there is no universally accepted method for

¹² Whole Person Care, RCPsych, April 2013.

¹³ Houses of Parliament (2015) Parity of Esteem for Mental Health.

measuring parity, one of the common concepts of measurement, which illustrate the current gaps in parity of mental health is excess mortality.

There is evidence that people with severe mental health difficulties have a reduced life expectancy. Those with severe mental health difficulties die an estimated 15-20 years before the general population. Furthermore, the bulk of increased mortality in people diagnosed with severe mental health difficulties is largely attributed to preventable physical health problems such as cardiovascular disease, obesity and diabetes.¹⁴

A recently published report by the Substance Abuse and Mental Health Services Administration (SAMHSA) in the US found that adults aged 18 or older with any mental disorder or major depressive episode in the past year were more likely than adults without these conditions to have high blood pressure, asthma, diabetes, heart disease, and stroke. The same study found that adults with 'serious mental illness' in the past year were more likely than adults without 'serious mental illness' to have high blood pressure, asthma, and stroke. In terms of health service utilisation, adults with any mental disorder used both emergency departments and hospitalisation more than those without a mental disorder. Similar results were found for those with severe mental disorders and those with major depression.

It is clear that ongoing gaps in achieving equivalent access to health care for people with mental health difficulties fall short of international human rights which recognise the rights of people with mental health difficulties to the highest attainable standard of health, on par with those of people with physical health difficulties.

Joined-Up Policies and Services

The objective that "people with disabilities and the NGOs that represent them are consulted about the way that services are designed and delivered" should be amended to ensure that individuals are not just consulted but involved at all levels of design and delivery.

The objective of "different public services working together" should encompass the importance all Government Departments working together to ensure the needs of people with disabilities are adequately addressed.

Conclusion

The themes identified in the consultation document are all relevant to people with mental health disabilities. Unless indicated above, Mental Health Reform supports the proposed objectives. It is important that specific actions are set out under each of the proposed themes to address the particular needs of this cohort of individuals.

The support system for people with disabilities has developed largely with people with physical, sensory and intellectual disabilities in mind. Supports such as disability benefits, for example, have been designed for people with permanent disabilities and do not cater well for people with mental

¹⁴ Achieving parity of outcomes, BMA Board of Science, May 2014.

health difficulties who have fluctuating work capacity, and for whom early intervention can minimise or eliminate disablement.

In the housing sphere, the system for identifying individuals with a disability-related housing need has depended on self-disclosure which has been a particular barrier for people with more severe mental health difficulties about whom there is a high degree of social stigma. The nature of mental health difficulties is also different from many other types of disability: mental health difficulties are at the same time invisible, intermittent and severely stigmatised. For these reasons, it is of fundamental importance that the Government takes this opportunity to include specific actions for people with mental health disabilities in the development of the National Disability Inclusion Strategy.

With regard to the relative priority for each of the themes, Mental Health Reform's opinion is that the proposed themes in the consultation document are all equally important to people with mental health disabilities.

The international community recognises that all human rights are indivisible, interdependent and interrelated. According to the Vienna Declaration and Platform of Action of 1993:

"All human rights are universal, indivisible and interdependent and interrelated. The international community must treat human rights globally in a fair and equal manner, on the same footing, and with the same emphasis."

All rights, whether the right to the highest attainable standard of health, including mental health, the right to work or the right to housing are equal in importance and none can be fully enjoyed without the others. All have equal status, and cannot be positioned in a hierarchical order. The fulfilment of one right often depends, wholly or in part, upon the fulfilment of others. For example, enjoyment of the right to health may depend on enjoyment of adequate housing or employment. For this reason, Mental Health Reform recommends that each of the themes be given equal weight.

Additional recommendation

In addition to the proposed themes and objectives, Mental Health Reform is of the view that it would be important to incorporate guiding principles into the strategy.

An overriding principle for the strategy should be fulfilment of individuals' human rights.