



National Federation of
Voluntary Service Providers

Supporting people with intellectual disability (CLG)



LISTEN TO OUR VOICES

Report on **Therapy Services for Adults**
with an **Intellectual Disability** in Ireland

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Foreword

This report aims to outline the challenges faced by people with intellectual disability in accessing therapy services, the levels of staffing within services, the unmet service requirements and the vision for future services.

In this report, the National Federation of Voluntary Service Providers' Board of Directors highlights the lack of therapy services available for adults with intellectual disability. The three primary policies in the area of intellectual disability (1) Progressing Disability Services for Children & Young People, (2) Time to Move on from Congregated Settings; and (3) New Directions: Report of the National Working Group for the Review of HSE Funded Adult Day Services are shaping the delivery of services nationally. In order to fully implement these policies, the National Federation advocates for the provision of enhanced therapeutic services that are key to meet the needs of adults with intellectual disability.

It was decided to convene a working group of therapists employed by member organisations of the National Federation with a view to (a) assessing the level of available therapy services and (b) developing a strategy to address the deficits in this area.

I would like to thank the members of the Working Group for all their work on gathering data and assisting with this important piece of work. I would like to thank in particular Marina Moore, Brian Muldoon and Renjith Joseph for all the time and effort they have put in to finalise this report, it is much appreciated.

This report is fully endorsed by the Board of Directors of the National Federation of Voluntary Service Providers.

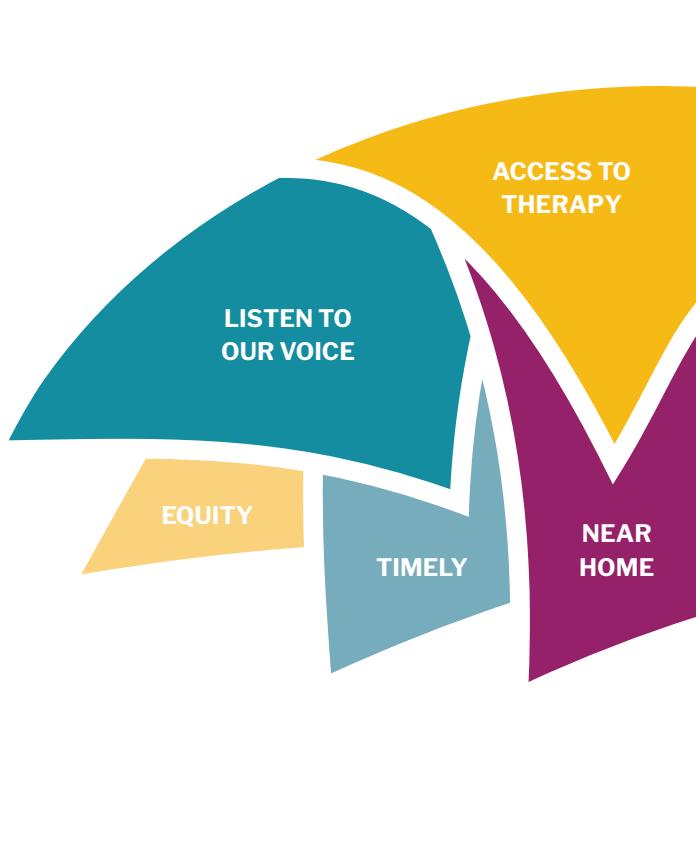
Bernard O'Regan

Chairman

Executive Summary

The National Federation of Voluntary Service Providers is committed to supporting the rights of people with intellectual disabilities to access therapy services. The National Federation recognises that the level of therapy service provision in Ireland currently does not meet the needs of one of our most vulnerable populations. Therapy services for adults are not appropriately resourced across the country and access to Primary, Community and Continuing Care for people supported by services is inequitable.

Research was conducted with adults with intellectual disabilities, their therapists and service providers in the area of therapeutic supports. A number of key findings emerged. The Federation studied these findings and have made recommendations on how to address these deficits in therapeutic supports. These recommendations were informed by recent government policies in the areas of general health and future service provision for adults with disabilities.



Section 1- Introduction

Members of the National Federation of Voluntary Service Providers are fully committed to supporting people with an intellectual disability to achieve real and valued roles, through active citizenship. We are committed to ensuring that children and adults receive high quality supports and services most suited to meeting individual needs, promoting inclusion and independence.

In 2016, the Board of Directors of the National Federation of Voluntary Service Providers, responding to concerns expressed by their membership, convened a Working Group to assess the provision of therapy services for adults with an intellectual disability in Ireland. The aim was to develop a strategy to address issues identified and draft a paper for submission to the Department of Health and the HSE. To date, the quantum of therapy services in Ireland for adults (18+) with an intellectual disability has not been well defined and those services that are provided do not meet the identified needs of adults. Sláintecare clearly acknowledges that the current provision of therapy services for adults with an intellectual disability is highly inequitable (Houses of the Oireachtas Committee on the Future of Healthcare, 2017).

Service provision is reliant on a post code lottery system. Furthermore, where therapy services to adults are available, some of these services have been negatively impacted by the introduction of Progressing Disability Services for Children and Young People (PDS). In areas where PDS has been implemented, therapists, who were previously split across both adult and child services, are now often aligned to children's services thus resulting in a reduction in therapy services to adults (National Disability Authority, 2018).

“There are a lot of difficulties with appointments. I understand that children have to be prioritised but the adults are being pushed back to a long list.”

Self Advocate

A number of factors will shape the development of therapy services for adults:

Policies & Legislation

- Time to Move from Congregated Settings (2011)
- Report of the Independent Review Group established to examine the role of the Voluntary Organisations in publicly funded health and personal social services.
- New Directions (2011)
- Disability Act (2005)
- Equal Status Act (2000), Equality Act (2004)
- United Nations Convention on the Rights of Persons with Disabilities
- Health Act (2007)
- Department of Health Workforce Planning for Health and Social Care (2016)
- Health Service Capacity Review (2018)
- A Vision for Change (2006)

Dementia in Intellectual Disability

- Incidence of dementia in ID - five times higher than general population (McCarron, 2018)
- Mean age of onset of dementia in Down syndrome is 55
- 88% of people with Down syndrome will develop dementia by age of 65

Assisted Decision Making

- Capacity Act (Assisted Decision Making) 2015 to support people to make decisions on their own life choices
- Health & Social Care Professionals provide support for assisted decision making

Increase in population of people with ID

- 8.4% increase in ID population between 2009 and 2016
- Expected rise of 121% in adults with ID over 50 between 2015 & 2025 (NDA, 2018)

Sláintecare

- Equitable services at the lowest level of complexity as close to home as possible.
- The right care, in the right place, at the right time.

Table 1: Factors shaping the development of therapy services

1.1 Policies and Legislation

Over the last two decades a number of national and international reports and policies have influenced the development of a biopsychosocial model of services for people with a disability in Ireland. National policies state that people with a disability have a right to equal access to the same health services as others, and access to a health service that is based on need rather than diagnosis. Progressing Disability Services for Children and Young People (PDS) is in the process of realigning therapy services to disability teams within the community services, thus allowing for a more efficient resource allocation and more equitable access to services. Unfortunately, this is not the practice in adult services where access to primary care and community services varies greatly across the country, is not equitable and depends on diagnosis rather than need. Furthermore, children born after 1 June 2002 are eligible to apply for an assessment of need under the Disability

Act. Therefore from 1 June 2020, a young person aged 18 can apply for an assessment of need in relation to their proposed adult service. This will impact on service providers already limited capacity to provide such assessments, which are mandated under law.

1.2 Dementia

Census 2016, reports that 66,611 persons in Ireland have an intellectual disability, representing one percent of the population and an 8.4% increase in population between 2009 and 2016; a period when spending on disability services fell by 7% (National Disability Authority, 2018). This demographic trend reflects an increase in the lifespan of people with intellectual disability resulting in an expected rise of 121% in the population of adults over 50 between 2015 and 2025 (Central Statistics Office, 2016). Incidence rates for dementia in people with intellectual disability are up to five times higher than in the general population (McCarron, 2018) (Strydom, 2013). Furthermore, adults with an intellectual disability are at increased risk of developing dementia at a young age and are often unable to access dementia care through traditional pathways for over-65s (Pierce, 2013). Without timely access to therapy services, many people with intellectual disability and dementia in Ireland are diagnosed at a very advanced stage in the progression of the illness and far later than the international average. Radical changes will need to be implemented in order to address the high level of demand for therapy services to meet the needs of adults with an intellectual disability and to support and manage the needs of an aging population (McCarron, 2010).

1.3 Sláintecare

The development of therapy services for adults with an intellectual disability, in particular services for people over 55 and people with dementia, must provide for equal access to the right care in the right place at the right time. We need to develop services in the community that prevent and reduce the need for admission to inpatient facilities. Sláintecare (2017) emphasises the delivery of care “at the lowest level of complexity” as close to home as possible that is community-based, and care that relates to clinical need rather than diagnosis. Access to Health and Social Care Professionals, experienced in the delivery of individualised person-centred supports for adults with an intellectual disability, will facilitate people supported by services to live within their community, to maintain existing relationships with family, community and friends and to live a life of their choosing. At present, the demand for therapy services for adults with an intellectual disability by far exceeds current capacity and this gap between demand and capacity will continue to grow as it expands.

1.4 Population

Nationally accurate figures on the numbers of therapy staff in the adult disability sector are not available. Over 2016 and 2017, the National Disability Authority (2018) collated data from the National Intellectual Disability Database on adults requiring new or enhanced therapy services. The data was striking, with the predicted demand for physiotherapy expected to increase by 90%, psychology and speech and language therapy services demand expected to increase by 115%, occupational therapy by 140% and dietetics to increase by 150%. In recent years there have been very few new development therapy posts funded to support adults with intellectual disabilities.

'It's a question of getting more of it. It's not a question of them being happy with it. It's a question of them getting more than they are currently getting'.

Self Advocate

'It seems they are not told no but they are left waiting for it which they are not being bluntly denied the service but they are left waiting and that is nearly the same as not getting it I suppose'.

Self Advocate

1.5 Assisted Decision Making

The Capacity Act (Assisted Decision Making) 2015 aims to support people to make decisions on their own life choices. Health & Social Care Professionals provide support for assisted decision making.



1.6 Summary

Chronic under-resourcing of multidisciplinary staffing levels for adults with an intellectual disability has resulted in a limited capacity for the development of any interdisciplinary or integrated care. The disparity of adult therapy services has been further compounded by the progression of services to the biopsychosocial, community based model thus placing further demands on the under-resourced services.

This submission is the outcome of consultation with people supported by services and consultation with member organisations of the National Federation of Voluntary Service Providers. It reflects the views of people supported by services and organisations who support adults with an intellectual disability.

The content gathered from the consultation process has been collated and summarised in this document.



Figure 1: Feedback from people supported by services



Figure 2: Feedback from organisations

'If you come from a wealthy family, you can get physio today because you have money to pay for it, but if you come from a middle class family, you have to wait to get seen by a physiotherapist or a speech therapist and that's not fair.'

Self Advocate

Section 2 - Mapping with Service Providers

A data mapping template was developed to gather information on what support needs and what levels of access to therapies adults with an intellectual disability have in Ireland. The initial questionnaire was piloted in three member organisations of the National Federation following which a number of amendments were made and the template was then circulated for completion to all of the National Federation member organisations.

Thirty-three of our sixty member organisations replied to the survey which represents a 55% response rate. We received at least one response in respect of each of the nine CHO areas and most of the larger service providers responded.

2.1 Data Collection

Service providers were asked for the following data:

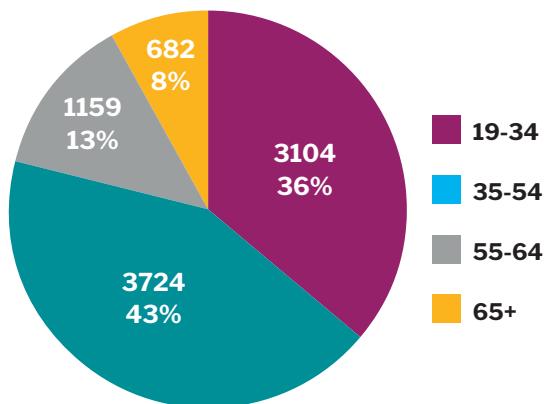
- Demographics on those supported by the service i.e. age profiles and levels of disability.
- Numbers of therapists employed, the source of funding of these posts, caseload numbers and waiting lists.
- Access to primary care for those living in congregated settings, in community based residential services or at home.
- Qualitative questions were also asked on the pressures placed on multidisciplinary support teams.



Figure 3: Map of CHO Areas

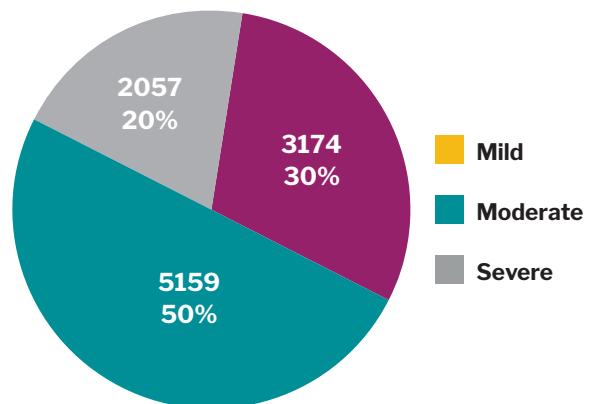
2.2 Results

Figure 4: Distribution of People by Age



Sample of people supported by age distribution.
Of significance is the 682 people over the age of 65.

Figure 5: Level of Disability



Level of disability of the sample. Of interest is the high proportion of adults in the mild range of ID.

2.3 National Multidisciplinary Staff Whole Time Equivalents (WTE)

Table 2 below outlines the total number of clinicians employed by the 33 participating service providers who support 10,656 adults with an intellectual disability.

	Total WTE
Physiotherapy	29.7
Occupational Therapy	37.9
Speech and Language Therapy	36.67
Psychology	55.76
Psychotherapy	0.81
Psychiatry	17.37
Behaviour Support	35.08
Social Work	71.63
Nutrition and Dietetics	7.35
Art Therapy	5.16
Music Therapy	5.87
TOTAL	303.3

The discipline with the largest number of clinicians employed by the Section 38 and Section 39 service providers who responded is social workers followed by psychologists. Occupational therapists, speech and language therapists and physiotherapists make up the next largest grouping of staff by discipline. Dieticians, art therapists and music therapists are only employed in small numbers by a few service providers.

Table 2: Total WTE clinicians providing therapy services across 33 Service Providers

2.4 Access to Primary Care Therapies:

CHO 1	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	N/A	N/A	N/A	100% (1/1)
Physiotherapy	N/A	N/A	N/A	100% (1/1)
Speech & Language	N/A	N/A	N/A	0% (0/1)
Dietician	N/A	N/A	N/A	0% (0/1)
CMH ID	N/A	N/A	N/A	100% (1/1)
Psychologist	N/A	N/A	N/A	100% (1/1)
CHO 2	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	0% (1/4)**	25% (4/4)	25% (4/4)	75% (4/4)
Physiotherapy	0% (1/4)**	0% (4/4)	25% (4/4)	0% (4/4)
Speech & Language	0% (1/4)**	0% (4/4)	0% (4/4)	0% (4/4)
Dietician	0% (1/4)**	0% (4/4)	25% (4/4)	25% (4/4)
CMH ID	0% (1/4)**	0% (4/4)	25% (4/4)	25% (4/4)
Psychologist	0% (1/4)**	0% (4/4)	0% (4/4)	0% (4/4)
CHO 3	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	0% (3/5)	0% (3/5)	60% (3/5)	60% (5/5)
Physiotherapy	0% (3/5)	0% (3/5)	60% (3/5)	60% (5/5)
Speech & Language	0% (3/5)	0% (3/5)	0% (3/5)	0% (5/5)
Dietician	20% (3/5)	20% (3/5)	60% (3/5)	60% (5/5)
CMH ID	0% (3/5)	0% (3/5)	0% (3/5)	0% (5/5)
Psychologist	0% (3/5)	0% (3/5)	0% (3/5)	0% (5/5)
CHO 4	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	0% (4/5)	0% (4/5)	20% (5/5)	40% (5/5)
Physiotherapy	0% (4/5)	0% (4/5)	20% (5/5)	40% (5/5)
Speech & Language	0% (4/5)	0% (4/5)	20% (5/5)	20% (5/5)
Dietician	0% (4/5)	0% (4/5)	0% (5/5)	40% (5/5)
CMH ID	0% (4/5)	0% (4/5)	0% (5/5)	40% (5/5)
Psychologist	0% (4/5)	0% (4/5)	0% (5/5)	0% (5/5)
CHO 5	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	28.6% (2/7)	28.6% (2/7)	71.4% (7/7)	57.2% (7/7)
Physiotherapy	28.6% (2/7)	28.6% (2/7)	71.4% (7/7)	71.4% (7/7)
Speech & Language	14.3% (2/7)	14.3% (2/7)	57.2% (7/7)	42.9% (7/7)
Dietician	28.6% (2/7)	28.6% (2/7)	71.4% (7/7)	57.2% (7/7)
CMH ID	0% (2/7)	0% (2/7)	42.9% (7/7)	42.9% (7/7)
Psychologist	14.3% (2/7)	14.3% (2/7)	42.9% (7/7)	28.6% (7/7)

CHO 6	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	0% (1/1)	0% (1/1)	0% (1/1)	0% (1/1)
Physiotherapy	0% (1/1)	0% (1/1)	0% (1/1)	0% (1/1)
Speech & Language	0% (1/1)	0% (1/1)	0% (1/1)	0% (1/1)
Dietician	0% (1/1)	0% (1/1)	0% (1/1)	0% (1/1)
CMH ID	0% (1/1)	0% (1/1)	0% (1/1)	0% (1/1)
Psychologist	0% (1/1)	0% (1/1)	0% (1/1)	0% (1/1)
CHO 7	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	0% (4/4)	0% (4/4)	50% (4/4)	50% (4/4)
Physiotherapy	0% (4/4)	0% (4/4)	50% (4/4)	25% (4/4)
Speech & Language	0% (4/4)	0% (4/4)	25% (4/4)	0% (4/4)
Dietician	0% (4/4)	0% (4/4)	25% (4/4)	0% (4/4)
CMH ID	0% (4/4)	0% (4/4)	0% (4/4)	0% (4/4)
Psychologist	0% (1/1)	0% (1/1)	0% (1/1)	0% (1/1)
CHO 8	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	100% (1/3)	0% (1/3)	100% (3/3)	100% (3/3)
Physiotherapy	100% (1/3)	0% (1/3)	33% (3/3)	66% (3/3)
Speech & Language	100% (1/3)	0% (1/3)	33% (3/3)	33% (3/3)
Dietician	100% (1/3)	0% (1/3)	33% (3/3)	33% (3/3)
CMH ID	0% (1/3)	0% (1/3)	33% (3/3)	33% (3/3)
Psychologist	100% (1/3)	0% (1/3)	33% (3/3)	33% (3/3)
CHO 79	Congregated Campus	Congregated Community	Community Houses	Home
Occupational Therapy	50% (2/3)	50% (2/3)	66% (3/3)	66% (3/3)
Physiotherapy	50% (2/3)	50% (2/3)	66% (3/3)	66% (3/3)
Speech & Language	50% (2/3)	50% (2/3)	33% (3/3)	33% (3/3)
Dietician	0% (2/3)	0% (2/3)	0% (3/3)	0% (3/3)
CMH ID	0% (2/3)	0% (2/3)	33% (3/3)	33% (3/3)
Psychologist	0% (2/3)	0% (2/3)	0% (3/3)	0% (3/3)

Table 3: Level of access to primary care for people supported

Key:	Congregated Campus:	Adults living in onsite residential (Congregated) based settings
	Congregated Community:	Where ten or more people share a single living unit in the community
	Community houses:	Adults in living in community houses
	Home:	Adults living at home

** 1 of the 4 respondents provide support in the campus based congregated setting and 0% of the residents living there have access to Primary, Community and Continuing Care (PCCC) Occupational Therapy.

The table on pages 10-11 shows that access to primary care for adults with intellectual disabilities varies across CHO areas, within CHO areas and can also depend on where the person lives. For example, over recent years CHO5 has enhanced the level of access to primary care and community services and this has welcomed new funding initiatives in this part of the country.

2.5 Caseload Example: CHO 2 – Population 1801

Table 4 below identifies the caseloads of clinicians in CHO2. CHO2 was selected for analysis of caseload figures as we received a 100% response rate from the four providers of intellectual disability services in this area.

Caseloads Example CHO: 2

		CHO 2 (Galway, Mayo, Roscommon)			
		Total WTE	Total Active	Total Inactive	Total Open Waiting
Physiotherapist		4	272	133	44
Occupational Therapist		3.04	138	132	216
Speech & Language		4.71	326	75	424
Psychology		9.7	615	69	223
Psychotherapist					
Psychiatry		2.8	605	0	5
Behaviour Support		2.95	141	156	50
Social Work		15.9	777	110	136
Dietician					
Art Therapist					
Music Therapist					
Other					
CHO Area	Age 19-34	Age 35-54	Age 55-64	Age 65+	No of Responses
2	754	732	201	114	4
		Population Totals - By Age			
		1801			

Table 4: Sample caseload data

Table 4 shows there are 1,801 adults with intellectual disabilities attending Section 38 and Section 39 services in CHO2. It is also noted that clinicians working in these services have large active and inactive caseloads and also significant waiting lists. Psychiatrists carry very significant caseload numbers, with many people supported by the services waiting for access to speech and language therapy.

2.6 Qualitative Data

This figure charts the most significant themes which emerged from the qualitative section of the questionnaire.



Figure 6: Common themes of need identified by service providers

The providers surveyed identified the following pressures on adult therapy teams: lack of multi-disciplinary posts, caseload demands, firefighting to respond to emergency cases, limited opportunities for joint working, lack of administrative support, responding to the challenges faced in supporting the implementation of HIQA action plans and working towards the delivery of various HSE/Department of Health national strategies.

Section 3 - Consultation with Self-Advocates on Adult Therapy Services

As part of the consultation with Self-Advocates a focus group was held on 26th November 2018 by the National Federation of Voluntary Service Providers and Brothers of Charity Services Ireland, West Region. The aim of the focus group was to discuss experiences and challenges of people with disabilities accessing therapy services.

The quotations used throughout the document are direct quotes from the self-advocates. It's important to highlight that these self-advocates are not only speaking about themselves, but on behalf of everyone that needs a service and can't access it. This is highlighted in the quote(s) below.

'I'm not here to talk about myself. I'm here to advocate for those who can't speak for themselves, and speak for those who need the service and can't get it'

Self Advocate

3.1 Waiting Lists

Overwhelmingly people are having trouble accessing the services they need in the first instance. There are long waiting lists within the services and people are frustrated because they cannot get access to the right therapy, in the right place, at the right time which is having a big impact on their lives. They said the Government are not hiring enough therapists.

'That is absolutely ridiculous. It is not the fault of the Occupational Therapists, the Physiotherapists or the Speech & Language Therapist. It is the fault of our Government'.

Self Advocate

3.2 Self-Funding of Services

Because of the long waiting lists, people who are in pain or need intervention are forced to pay from their own money in order to see a private therapist. They said people with money who can afford to pay can get an appointment within weeks, whereas, people with medical cards are put on a long waiting list. They feel this is very unfair to people with disabilities.

'People with medical cards cannot get it today. They have to wait for maybe a year. It's not fair.'

Self Advocate

3.3 Delayed Intervention

There are also issues in relation to getting a follow up appointment. Once people receive their first appointment, they have to wait long periods for another appointment. This can have devastating consequences for people who are in pain and who need therapy on a regular basis. The people supported strongly emphasised if they don't receive the right care that their quality of life will decrease significantly, and this could result in them needing full time care. Apart from the devastating personal implications of this they said this will also result in costing the state more money in the long run.

'If you are in a wheelchair all the time you are going to stiffen up. The next thing you are not going to be able to stand up and you are going to fall. Then you are left in a bed for the rest of your life.'

Self Advocate



3.4 Good Quality Care

There seems to be no issue with the quality of the therapy received. The people in the focus group were very happy with the quality of service and spoke of how nice and professional their therapists were. The problem for them is being forced to wait for long periods for appointments and not receiving follow up treatments on a regular basis.

'I was very happy with the service I got yes. I was happy when I got it. But still I do need more. My leg needs that stimulation.'

Self Advocate

3.5 Message to the Government

The people who took part in the focus group spoke of how they feel isolated and forgotten about by the Government. As was stated previously they feel the Government is not hiring enough therapists which means that people are left waiting for a service for a long time. They would like for politicians to honour the promises they make at election time – again the quote below emphasises this.

'We have people in this country that need a service. If there was an election tomorrow morning there would be no problem with money. There would be posters here, posters there and posters everywhere....! But once the election is over the money does not exist. All the promises are broken"

Self Advocate



3.6 Listen to our voice

The focus group want to talk to the politicians as they feel they don't understand their struggles. In order to make the services better for people, members of the focus group are urging members of the Government to sit down and speak with them and listen to their experiences. They want to tell them first-hand about the challenges they face on a daily basis.

'They (our Government) need to sit down with us and meet us and trash these matters out.'

Self Advocate

3.7 Therapy is a necessity not a luxury

The self-advocates wanted the Government to know that access to therapy services is a necessity not a luxury.

'These services are essential to us so that we do not go backwards physically and that we can live independently. And it is going to cost the state more in the long run if two people are needed to get someone out of bed. Plus, it keeps people out of a nursing home'

Self Advocate

'Keeping your body working is very important. If you lose that you lose your independence. You are gone and that is it'

Self Advocate



Section 4 - Unmet Service Requirements in Therapy Services for Adults with an Intellectual Disability

Feedback was received from the following disciplines:

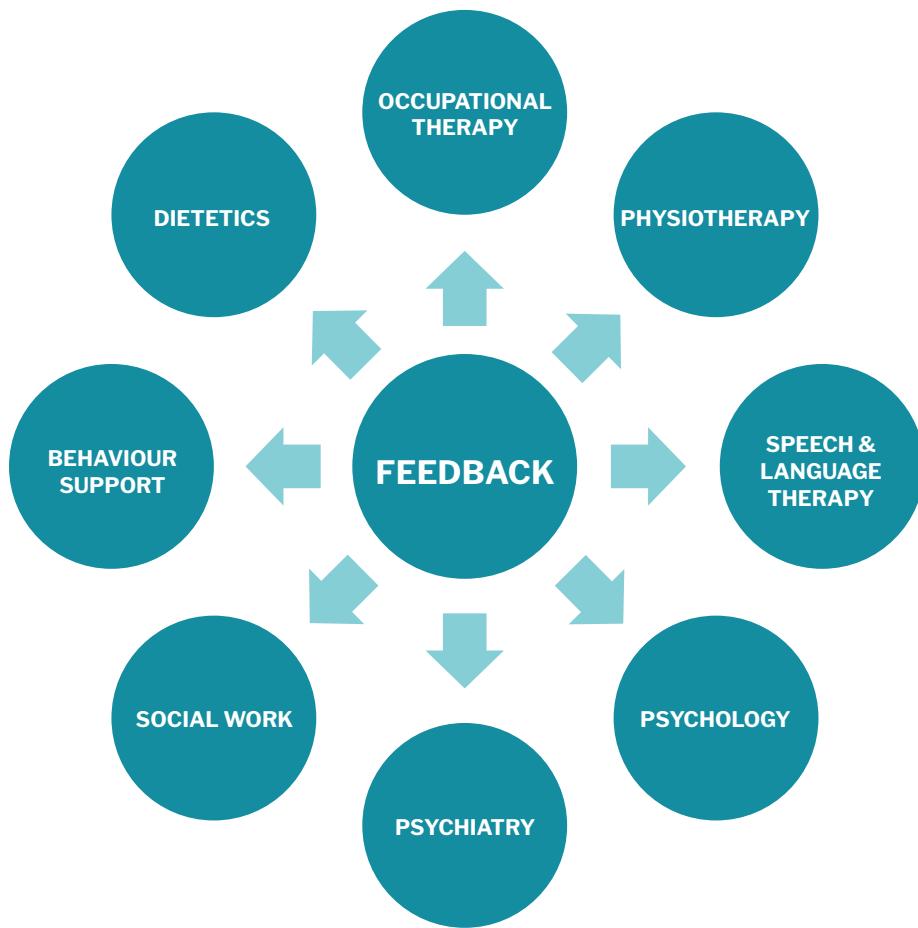


Figure 7: Disciplines that provided information on unmet needs

In the consultation process unmet service requirements were identified within current therapeutic service provision for adults with an intellectual disability. Feedback was sought from multi-disciplinary teams working across member organisations. In total nine organisations and eight disciplines contributed.

Common challenges were listed under the five assigned categories:

- Challenges in Service Provision with Existing Resources
- Young Adults / School Leavers - Age Group 18 - 22
- Adults -Age Group 23-50
- Older Adults Age Group 50+
- Palliative Care

Figure 8: Categories of challenges to service provision

Challenges in Service Provision with Existing Resources:

The following themes were consistently raised as challenges by all disciplines:

- Lack of administrative support;
- Implementation of HIQA action plans without resources;
- Loss of posts to children's services;
- Difficulty accessing Primary Community and Continuing Care;
- Mental Health Intellectual Disability teams not yet fully established.

'It's a disgrace really, people with a medical card end up at the back of it. Long waiting times. It's ludicrous'.

Self Advocate



Young Adults / School Leaver - Age Group 18 – 22:

Common themes raised by the disciplines for this age group were:

- Planning for the transition to adult services;
- Inadequate transfer of information from children to adult services;
- Limited alternatives available to traditional day service model;
- Lack of funding for multidisciplinary new posts to provide services to school leavers;
- Inadequate provision of respite;
- All the above unmet needs have a negative impact on people supported and their families.

'I don't think I was ever told I could not have a service, but I was told I might have to wait a long time for it'.

Self Advocate

Adults - Age Group 23-50:

This group of adults present with the same healthcare needs as their peers, but with more risks and additional specialist needs. Health care needs are not well supported in mainstream services. The following unmet needs were identified:

- Falls prevention and bone health;
- Screening for cognitive age related decline;
- Loneliness;
- Poor quality of life;
- Lack of work opportunities;
- Lack of independence training;
- Lack of community supports;
- Lack of activity sampling;

- Requirement for health promotion;
- Increased supports required for relationships;
- Needs of the ASD population are not well served.

'When it comes to an election they are not doing enough. Last year before the election they made promises. They did not keep them. They did not do what they said they would. They made promises they did not keep"

Self Advocate

Older Adults - Age Group 50+:

The changing needs related to an ageing population are not adequately resourced. The challenges identified for this age group were:

- Increased demands given ageing population;
- Inadequate resources to respond to changing needs;
- Falls prevention;
- Specialised seating;
- Specialist dementia supports required;
- Increasing needs for aids and appliances;
- Joint working across disciplines required e.g. dysphagia;
- Inadequate future planning for retirement and housing requirements;
- Ageing family and lack of respite.

'Within the Inclusive Research Network, we have a couple of members that have to go into a nursing homes because of a lack of services in the outside".

Self Advocate

Palliative Care:

Specialised End of Life supports require multi-disciplinary teams.

- Increasing supports required for ageing in place;
- Limited resources;
- Staff training required e.g. tissue viability, nutrition, dysphagia, end of life care, bereavement;
- Policy development;
- Specialist staffing and CPD required;
- Adequate time to support decision making and end of life care planning.

'You have to confront these matters or it will be downhill as people who need physio you will be confined to bed.'

Self Advocate



Section 5- Vision

The vision of the surveyed members of the National Federation of Voluntary Service Providers is to support adults with an intellectual disability to live life on their terms by focusing on:

What:

Adults with an intellectual disability, their families, and carers require support from multi-disciplinary team (MDT) personnel. This is in the form of both direct therapeutic inputs, which focus on the individualised support needs and choices of people, as well as intervention at the service / community level, to support social inclusion, community support and person centeredness within local communities.

Why:

Quality and effectiveness: Therapeutic interventions provided by the core disciplines of occupational therapy, speech and language therapy, physiotherapy, psychology, social work and dietetics, are based on evidence based approaches to ensure the highest standard of care and optimum use of resources.

HQIA standards and regulations of the Health Care Act, 2007 require that adults with intellectual disability have access to support from staff who have the appropriate knowledge, skills and competence to support them in living well. Evaluation of therapeutic outcomes for people supported by the service ensures that efficacy and quality of therapeutic interventions is monitored, making sure that MDT resources are used optimally.

'I want everyone to be treated equally. I would hope the government would come out of their offices and have a good look around at what needs to be done. They need to see what is happening day after day night after night.'

Self Advocate

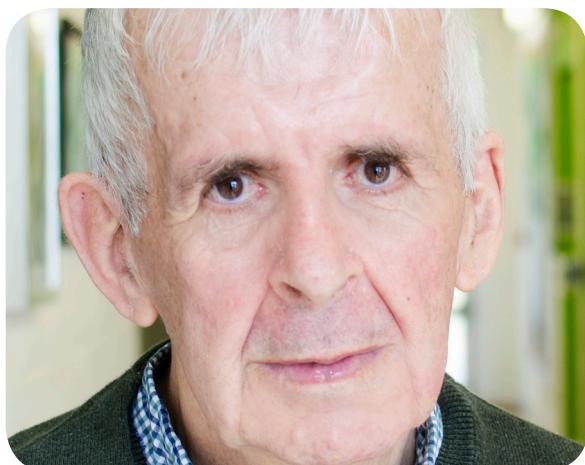
How:

Multidisciplinary Teams:

- Work to empower people with an intellectual disability; they actively support advocacy ensuring the voices of people with an intellectual disability and their advocates are heard in the development of meaningful social roles within local communities;
- Work collaboratively with other staff members in sharing knowledge and building their skills and competencies to ensure meaningful partnerships are established in the planning and delivery of therapeutic interventions throughout the individuals' day to day life;
- Have highlighted the need for multi-agency working across sectors including mainstream and primary care services. These services should be accessible to adults with an intellectual disability due to for example, age related concerns;
- Work flexibly, providing sufficient clinical services that are responsive to individual changing needs.

'It's a question of getting more of it. It's not a question of us being happy with it. It's a question of getting more than we are currently getting.'

Self Advocate



Section 6-Recommendations

The following recommendations are made based on a comprehensive consultation with the member organisations of the National Federation of Voluntary Service Providers and people supported by services on the provision of therapy services to adults with intellectual disabilities:

Future model of services for people with an intellectual disability should incorporate the following:

- Further consultation with the people supported by services and their representative advocacy groups on the future model of therapeutic service. The question of whether these services are embedded within current intellectual disability services or accessible via the community needs to be addressed;
- Consideration of therapeutic support needs should be included in all future national health care strategies;
- Development of therapeutic services should be aligned with national strategic healthcare policies;
- Prioritise health promotion, prevention and wellbeing;
- Develop of integrated, person centred models of care;
- Therapeutic supports to deliver joint packages of care;
- Planning for retirement, supports and future housing requirements for an aging population;
- Development of integrated package of palliative care for people with intellectual disability;
- End of life care planning.

Therapeutic services for people with an intellectual disability should be equitable:

- Sláintecare acknowledges that adults with an intellectual disability do not have equal access to services that allow for delivery of “the right care, in the right place at the right time” (Sláintecare, 2018);
- Services should be equitable across the nine CHO areas;
- There should be a seamless transition for people when they are moving between services such as transferring from children’s disability teams to adult services;
- There should be a seamless transition between services for people when they are moving from hospital settings to adult services;
- Equitable access to aids and appliances.

Investment of resources to meet the needs of adults with an intellectual disability:

- Comprehensive workforce planning is required to identify gaps in national delivery of therapeutic services;
- Increase staff capacity to meet current demands;
- Development of specialist service to meet the changing needs of the aging population (Transforming Lives, 2018);
- Development of specialist services for people with intellectual disability and dementia;
- Increase access to home care packages;
- Enhance of old age psychiatry services for people with intellectual disability;
- Administrative support is essential in order to maximise the delivery of therapeutic services;
- There is an increased requirement for respite and residential placements;
- Develop of specialist services for palliative care.

References

- Central Statistics Office. (2016). Census 2016. Dublin: <https://www.cso.ie/en/census/>.
- Department of Health. (2014). *The Irish National Dementia Strategy*. Dublin: Department of Health.
- Department of Health and Children (2006). *A vision for change: Report of the Expert Group on Mental Health Policy*.
- Department of Health Workforce Planning for Health and Social Care (2016).
- Department of Health (2018) Sláintecare.
- Government of Ireland (2007). *Health Act*. Dublin: Government Publications.
- Government of Ireland (2015). *Assisted Decision-Making (Capacity) Act*. Dublin: Government Publications.
- Government of Ireland (2005) *Disability Act 2005*. Dublin: Government Publications.
- Government of Ireland (2000) *Equal status Act*. Dublin: Government Publications.
- Government of Ireland (2004) *Equality Act 2004*. Dublin: Government Publications.
- HSE (2011). *Time to Move on from Congregated Settings – A strategy for Community Inclusion* <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/>
- HSE (2014). *The National Dementia Strategy*. Dublin: Department of Health.
- Health Information and Quality Authority. *National Quality Standards for Residential Settings for Children and Adults with Disabilities*. Dublin: Health Information and Quality Authority; 2013.
- Health Service Executive (2012). *New Directions Review of HSE Day Services and Implementation Plan 2012 – 2016. Personal Support Services for adults with Disabilities*.
- Houses of the Oireachtas Committee on the Future of Healthcare. (2017). *Houses of the Oireachtas Committee on the Future of Healthcare Slaintecare Report 2017*. Dublin: Houses of the Oireachtas.
- Pierce, S. C. (2013). *Planning dementia services: new estimates of current and future prevalence rates of dementia for Ireland*. Irish Journal of Psychological Medicine / Volume 30 / Issue 01 / March 2013, 13-10.
- McCarron, M. (2018). *Ageing with Down Syndrome: Latest Insights*. Dublin: IDS-TILDA, Trinity College Dublin.

References (continued)

National Disability Authority (2015) New Directions: Report of the National Working Group for the review of HSE Funded Adult Day Services. <https://www.hse.ie/eng/services/list/4/disability/newdirections/new%20directions%20report.pdf>

National Disability Authority. (2018). Transforming Lives: Report on Future Needs for Disability Services 2018. Dublin: Government Publications.

Strydom A, C. T. (2013). Incidence of dementia in older adults with intellectual disabilities. *Res Dev Disabil.*, 34(6), 1881-5.

UN General Assembly. Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: <https://www.refworld.org/docid/45f973632.html> [accessed 12 May 2019]

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