



INDEPENDENT LIVING
MOVEMENT IRELAND

FREEDOM • RIGHTS • EMPOWERMENT

www.ilmi.ie

(Image shows ILMI logo with Text: Independent Living Movement Ireland. Freedom, rights, empowerment and website address www.ilmi.ie)

Independent Living Movement Ireland overview of the Department of Health “Disability Capacity Review to 2032: A Review of Disability Social Care Demand and Capacity Requirements up to 2032”.

Introduction to Independent Living Movement Ireland

Independent Living Movement Ireland (ILMI) is a campaigning, national Disabled Person’s Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society. Central to the way we work is to ensure that policy decisions that impact on the lives of disabled people have to be directly informed by those whose lives are directly affected.

Our philosophy can be summed up as: ‘Nothing about us without us!’ and ‘Rights Not Charity’. Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

Social model of disability

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) at its core is framed through an understanding of disability known as the social model of disability. From ILMI’s perspective, it is vital that there is a clear and full understanding of what the social model of disability is and how it should inform future discussions on policy development and improvement and policy implementation.

The social model looks at how society is structured and how it disables people. It is not based on a person’s impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. In this

model it is society that disables people from achieving their hopes and dreams, not a person's impairment. The social model informs all aspects of the work of ILMI.

Language and representation of disabled people

Independent Living Movement Ireland recognises that language is a very powerful and evocative tool. Therefore, the language and terminology used in this review has been carefully chosen to reflect the values of equality and empowerment which is at the core of this organisation. The term ‘disabled people’ has been used throughout this review in accordance with the UPIAS classification of disability and impairment which has been developed by disabled people themselves (UPIAS 1976). Where disabled people are referred to in the submission this should be understood to include all disabled people, including those with learning difficulties, people experiencing emotional distress and physical and sensory impairments.

Executive summary

The Disability Capacity Review sets out State investment for the next 10 years without referencing what disabled people need and want. It is based on continuing to invest in the “Disability Industry” which will perpetuate a situation where many disabled people are segregated from society and makes little reference to State and International policy to invest in ensuring the full inclusion in society with the supports they need to do so. The Disability Capacity Review worryingly looks to expand “services” that are based on the premise that non-disabled people know best and need to make decisions on what disabled people want. This is completely contrary to the obligations set out in the UNCRPD.

Please see ILMI recommendations on pages 14, 15, 16 and 17.

Policy context

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Ireland ratified the UNCRPD with legally binding obligations to “undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability (Article 4).

According to Article 1 the purpose of the CRPD “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” It acknowledges that all disabled persons are right holders and that impairment cannot be used as a justification for denial or restrictions of human rights. It recognises disability as a social construct which is caused when impairment interacts with societal barriers. It is a as a paradigm shift from the medical to the social model of disability.

The UNCRPD makes specific references to state party commitments to ensure disabled people are effectively involved in all policy forums. **Article 4.3 states:** “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.” **General Comment 7.13** of the CRPD states that: “Organisations of persons with disabilities should be distinguished from organisations “for” persons with disabilities, which provide services and / or advocate on behalf of persons with disabilities, which, in practice, may result in a conflict of interests in which such organisations prioritise their purpose as private entities over the rights of persons with disabilities. States parties should give particular importance to the views of persons with disabilities, through their representative organisations, support the capacity and empowerment of such organisations and ensure that priority is given to ascertaining their views in decision-making processes.”

Article 29. B outlines actively promoting an environment in which disabled people can “effectively and fully participate” in public affairs, without discrimination and on an equal basis with others. Article 29 B also states participation of disabled people in non-governmental organisations and associations concerned with public and political life. Most importantly article 29 B states disabled people should be involved in “forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels”. For far too long

disabled people have been excluded from participation in decision making structures at all levels.

“Nothing about us without us”: the role of Disabled Persons’ Organisations (DPOs) DPOs, unlike disability services providers, are led by and for disabled people. It is vitally important that this is understood to ensure that disabled people have their contributions heard, represented and recognised in policy development.

Article 12 – Equal recognition before the law specifies that disabled people are equal before the law and have the right to recognition everywhere as persons before the law. It states that disabled people should enjoy legal capacity on an equal basis. The state should take appropriate measures to provide access by disabled people to the support they may require in exercising their legal capacity and that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Article 12 also outlines that the state shall take all appropriate and effective measures to ensure the equal right of disabled people to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit.

Article 19 Independent Living outlines that disabled people have the right to live in, be part of, and use services and amenities in their communities. They should choose where and with whom they live with appropriate and adequate supports. While

Article 23 Respect for the Home and Family recognises that disabled people have the same rights as others to parenting, relationships and family planning.

Article 25 Health outlines Disabled people have the same right as others to access mainstream and specialist health services in their communities. They should experience the same standard and quality of care as others.

The central policy objective for disabled people is contained in “**Towards 2016**”; that people should be supported “to lead full and independent lives, to participate in work and society and to maximise their potential”. The **National Disability Inclusion Strategy (NDIS)** states that “for the last 15 years it has been established

Government policy that mainstream public services include and serve” disabled people, which is underpinned by the Disability Act 2005.

Despite ratification of the UNCRPD, and enactment of various equality and disability related legislation and policy Ireland has, and currently continues to promote a medical / charity view of disability. This is evidenced by the fact that many of the supports and services developed by non-disabled people have been / are funded by or through the Department of Health and the Health Service Executive (HSE).

The **Value for Money and Policy Review of Disability Services in Ireland (2012)** proposed “a fundamental change in approach to the governance, funding and focus of the Disability Services Programme, with the migration from an approach that is predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports”.

It states that “future delivery of services and supports to disabled people should acknowledge the views of stakeholders – that choice, control, independence and community inclusion are the keys to an effective, person-centred service”.

The “**Transforming Lives programme to implement the recommendations of the “Value for Money and policy review of disability services in Ireland” (2018)** stated its commitment to “improving the delivery of health and social care services to people with disabilities, arising out of the Value for Money and Policy Review of Disability Services in Ireland, based on enshrining the principles of self-determination and autonomy in all service provision for those with disabilities.

The HSE “**New Directions: Report of the National Working Group for the review of HSE Funded Adult Day Services**” is based on the principle of disabled people being included in society and recognises that segregated day services are contrary to that principle:

“Having choices, doing interesting and useful things with one’s time, learning new skills, meeting people and enjoying their company – these are things that most people take for granted. These are the ordinary experiences that people with disabilities tell us they want. The way in which adult day services has

evolved over the years has tended to get in the way of these reasonable expectations. **Our adult day services have, for the most part, been organised as segregated services, separate from local communities and offering limited options, experiences and choices.** This report is making radical proposals and recommendations to change that”.

The HSE New Directions website notes that “the Benchmarking Exercise completed in 2015 confirmed that there is a commitment to change this and many service providers have moved ahead and commenced an approach to service delivery that focuses on the provision of supports. **However, the day service sector is most diverse and significant service change and reconfiguration has yet to be progressed”.**

Indeed, an internal Department of Health review of Disability policy confirms that whilst the rhetoric of inclusion, mainstreaming and person-centred services:

“There is little evidence of individualised service provision, with a lack of standardised needs assessment and provision largely based in groups. Even though many services purport to use person-centred planning, the quality of the person-centred plan can be negated if options are framed largely in terms of the current model of provision. For example, some day services may be described as supporting ‘community participation’, although this often involves service users attending a community setting as a group, on a special bus, often in a segregated manner (for example, a special hour for swimming or bowling). Those attending in the group usually have not selected that activity themselves. This is very different to an individual choosing to attend a swimming lesson, travelling to the swimming pool on public transport and taking the lesson with just a support person (not necessarily a health or social care professional).” Moreover Ireland has policies such as a **“Time to Move on from congregated settings”**: a national plan for the process of de-institutionalisation of intellectually and physically disabled people from congregated settings to the community coupled with the publication of **“Wasted Lives”** report and the development of a **new housing strategy for Disabled people**. All of which support that disabled people should live in their communities with choice and control.

The Disability Capacity Review to 2032: what does it say?

The glaring absence in the Disability Capacity Review is the absence of any sense of what disabled people want. It is a comprehensive review of what is currently provided in terms of services to disabled people, how much each of these services cost and detailed projections based on current unmet need and future population growth in the next ten years. All of this research is welcome but the conclusions it draws are ultimately flawed as at no point are references made to the above national policy commitments to move towards the supports that disabled people want and need to lives where they have control and choice.

The Disability Capacity Review (hereafter referred to as the “Review”) states that:

“A key priority is to continue to deliver on the strategic aims and recommendations of the significant work and research of the Value for Money and Policy Review of Disability Services (2012). The priority objective is to address the need for a better service model for people with a disability where greater flexibility, choice and control from the service user perspective is central. Under Transforming Lives, the focus is on developing individualised person-centred supports to enable people with disabilities participate to their full potential in economic and social life in the community and be enabled to live ordinary lives in ordinary places. It involves fundamentally changing how we deliver services; delivering on this level of change is a challenge and significant progress is already underway to achieve integration rather than segregation in line with the following policies.”

Yet the majority of the report focuses on simply scaling up day services or residential services based on projected population growth, with little or no reference to directly investing in disabled people themselves and the supports they want, as outlined in all the national and international policy commitments above.

The Disability Capacity Review Data

The review states that roughly 9% of disabled people engage in disability services (approximately **56,000 people**), through a suite of interventions including early

intervention, multi-disciplinary therapies, habilitation, rehabilitation and behaviour support, staffed supported housing, specialist end of life care, respite / short breaks to support carers, day services and support for community engagement, personal assistance, home help and assistive technology.

Currently there is almost €2 billion invested in disability services through the HSE broken down by the following: Residential Care (64% of budget), Day Services (21% of budget), Respite (3% of budget) and the remainder on Home Help, Home Care, Personal Assistance, Assistive Technology and therapies. Of that €2 billion for 2019, over 27% of specialist disability services are provided directly by the HSE, almost 70% of services are provided by voluntary organisations funded under Section 38 or Section 39 of the Health Act 2004 and the remaining 4% provided by private sector bodies.

Personal Assistance Services

Just under 11,000 people currently receive Home Support or Personal Assistance hours – roughly twice as many hours are given in the form of Home Support. The 2018 budget breaks down roughly as €55 million for Home Support and €32 million for PA services.

About 2,500 people get a PA service averaging around 12 hours a week, and around 8,000 people get home support hours averaging around seven hours a week.

The information in the review confirms that from 2008 to 2018 there was no increase in the number of hours under the personal assistance services (PAS). It also confirms that there is a huge unmet need and that for the majority of people in receipt of PAS, the support they get does not allow them to live independent lives. It also notes that the lack of increased hours mean the disgraceful practice of reducing one disabled person's hours to meet another's needs is confirmed as policy.

In terms of unmet need, the following paragraph is instructive:

“While the organisations working in the area of physical and sensory disability report considerable shortfalls in the level of provision relative to need, there are little or no usable data on the scale involved. This is because it has not been the practice by

service providers or the HSE to document unmet need for these services. The budget for PA services has remained unchanged since 2008, so the HSE has been managing a fixed number of support hours each year. As a result, as reported to the Dáil, **the HSE may from time to time reduce an individual’s support hours in order to address priority needs of other people with disabilities within that community**. A high volume of representations and Parliamentary Questions on the topic is another indicator of the pressures on the system that are not being met. As unmet need had not been systematically recorded, the National Physical and Sensory Disability Database (NPSDD) and the National Intellectual Disability Database (NIDD) have only captured negligible levels of unmet need, be that those without any service, or those whose hours of support are below what they currently need”. The review notes that “there has been some substitution of PA or home care for respite, but no overall increase in support hours available. Pent-up demand for residential placements and respite from people on the emergency list has resulted in the increased usage of in-home support hours as a holding strategy to somewhat ameliorate the high risks in the home. This consequently limits the availability of hours to other disabled people requiring home care or Personal Assistance”.

In terms of what has been provided, the figures in the review reinforce the ILMI #PASNOW campaign that the majority of people receiving PAS are unable to live independent lives:

“Two thirds of those with PA support receive fewer than ten hours support a week, and only 7% receive more than 40 hours (Table 35). A PA service of two hours or less a day is unlikely to be able to go much beyond the provision of basic personal care, or **unlikely to enable someone achieve independent living**”.

The review breaks down the figures of hours received as follows:

Hours of PAS per week	%
1 to 5 hours per week	44%
6 to 10 hours	24%
11 to 20 hours	17%
21 to 40 hours	10%

41 to 60 hours	3%
60 plus hours per week	2%

In terms of the core findings of the Review, it estimates that in order to address unmet need, alongside demographic change, would require current disability spending in 2032 to rise by €550 million to €1,000 million, above its 2018 level. Of that possible €1 billion increase, to meet unmet need and increase hours with paltry PAS packages, it is proposed to allocate **€30 million or 3%** of this budget increase for a fundamental resource to support Independent Living. Again, this shows that the Review is based on perpetuating systems and structures that prevent disabled people having choice and control, despite the commitments to achieving that in all Statutory Policies.

Residential care

The Review notes that about 8,300 disabled people are currently living in residential settings with, 90% being people with an intellectual impairment at an annual unit cost of around €144,000. The most common form this takes is a group home, an ordinary house in the community shared ideally by no more than four people, along with support staff.

The review notes that there still are about 2,100 disabled people who live in ‘congregated settings’, despite commitments from a **“Time to Move on from Congregated Settings”** (2011). The review notes that after seven years of policy, by the end of 2018, the number of people residing in these centres had reduced from 3,401 in 2012 to 2,136. However, only just over 800 people had actually transitioned to the community over this period, while **almost 700 had died**. It is an indictment of policy that the figures showing reduction include almost as many disabled people who died as opposed to achieved a right to a home outside of an institution.

A further 102 people were scheduled to transition to the community in 2019. The review notes that there will need to be capital spending for housing to meet residential care needs and complete the closure of residential institutions which could cost in the region of €500 million to €800 million over the period to 2032.

The review notes the development of a new housing Strategy for Disabled People, and states that “to deal with both the backlog and with demographic change, overall an extra 1,900 residential places would be needed by 2032 under the minimum scenario, and an extra 3,900 under the Pre-recession scenario”, with the latter costing €550 million annually. It is not clear if this is to be funded to provide housing for disabled people in the community or whether it is solely to be invested to “support housing in the community shared by a group of four to six people with disabilities, known as group homes, but there are other forms of residential support” which would be contrary to Article 19 of the UNCRPD to give disabled people the choice of who they want to live with.

Adult day services

The review references New Directions and its aims to empower people to make their own choices and access activities in their own community, but makes no reference to the HSE’s own concerns about the fact that “reconfiguration has not progressed” or its own internal policy review which states:

“The current provision of disability services is not just located in and funded by health, but is strongly influenced by a ‘professionalised’ model of provision. This model has professionalised need, such that needs are assessed from the point of view of what health and social care professionals can offer and what disability services can offer. This has significant consequences for how disability services are organised and delivered, and also on the overall cost of services. The activity of the services is largely focused on providing services in group settings, most of which are segregated from the general community. The current structure and procurement of disability services is focused on continued provision of services in this way. **The additional funding that was available in recent years was focused on providing ‘more of the same’ in terms of structures and places, rather than addressing individual needs in individualised, flexible ways.**”

The review states clearly that ‘**Transforming Lives**’ is not working and that “Participation in day services is virtually lifelong”. Despite the Department’s own internal analysis and the clear preferences for disabled people to access supports to be fully included in all aspects of social, cultural, educational and economic aspects

of life, the review suggests that “the combined additional costs of demographic demand and unmet need could fall within a range of an extra €90 million to €280 million a year required by 2032.

Bear in mind, 21% of the almost €2 billion spent on disability services are already spent on Day services (approximately €420 million). It is proposed to possibly increase that by €280 million for a service that the Department internally admits “**providing ‘more of the same’** in terms of structures and places, rather than addressing individual needs in individualised, flexible ways”. Comparing the fact that the PAS currently is funded by the HSE to the tune of €32 million (a mere 7% of the Day Centre current budget) and the proposed increase in PAS and Day centres would mean the increased budget would only be an 8.2% of the overall day centre budget and you can see that there is a significant gap in policy and implementation.

In conclusion, the Review hints at the need for greater mainstreaming to “integrate into mainstream life in the community” and that there have “been positive experiences among those young people who have secured deferment of a day service place, and many have chosen to continue in the mainstream.” Yet as opposed to investing in those supports at transition points, the State is proposing, against its own policies and the wishes of disabled people to further invest in the provision of segregated day services.

The review notes that investing in ‘community connector’ roles to link disabled people with what “is happening in their communities, all who have a role to play in enhancing the ability to support people with disabilities in the mainstream” and reduce the need for “specialised disability supports”.

Health care

The review recognises the Sláintecare model “where the majority of healthcare is provided in the community through integrated primary and social care” and that “in principle, people with disabilities may access mainstream therapy services delivered via primary care”. The review states that it is often “difficult” for some disabled people to access generic community service. It also notes that “section 26 of the Disability Act 2005 places a duty on public bodies to include people with disabilities in

mainstream services, where practical and appropriate. Equal access to health treatments is also a key theme in Article 25 (Health) of the UN Convention on the Rights of Persons with Disabilities”.

Rather than audit where those access issues are and commit to investing in a genuinely inclusive universal health care delivery (as proposed under Sláintecare), the review shows that in 2018, specialist disability therapy services accounted for €84 million or 4% of overall disability expenditure. It also notes that the segregation of disabled people not surprisingly has an impact on their access of mainstream healthcare provision: “, those living with family had the best level of access to mainstream services, and those in congregated settings, the least access, and with group homes and congregated community settings in intermediate positions”.

Combining unmet and demographic needs, it is estimated that spending on therapy services needs to increase by around €50 million a year, rising to around €54 million a year by 2032 if those needs are to be addressed. In order that disabled people are accessing mainstream healthcare as per Article 25 of the UNCRPD that disabled people have “the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” this investment in specific therapies be delivered from mainstream primary health care facilities, and not through segregated provision. This would ensure that the mainstream has inclusion of delivery of services embedded and that all disabled people are accessing their local mainstream healthcare services.

ILMI recommendations for the implementation of rights based services

- The capacity review quotes €32 million for personal assistance services. ILMI would seek an increase to €96 million for Personal Assistance Services (PAS) in Ireland.
- It is welcomed that the Department finally recognises the huge un-met need in terms of Personal Assistance Services, which is something that disabled people want.
- ILMI calls on investment in disabled people and not the “disability industry”. For example we know from the capacity review it costs €25,000 to place a disabled person in day services for a year. We also know some disabled people who receive a PAS get on average 12 hours a week of PAS (two hours per day). However, if that €25,000 was given to the disabled person in the form of a personalised budget, they would receive significantly more than 12 hours per week and have full choice and control over their life.
- Currently at CHO level disabled people’s lives and supports such as PAS are discussed at “community discussion forums” or “clearing house committees” with the disabled person not present. Personal Assistance Services (PAS) must be a demand led service with the disabled person (often referred to as the leader) at the centre of the decision making process.
- A significant portion of funding should be diverted away from the institutions’ budgets. The PAS has to be increased to the level now recommended in order to see it attaching to the dismantling of residential care / day services in respect of de – congregation and in line with our many national policies and obligations under UNCRPD.
- Personal assistance services should not be mixed with homecare funding. These services are distinctly different. The Government should invest in PAS allowing disabled people to have choices equal to others. The design and governance of any PAS must involve the lived expertise of disabled people/Leaders. PAS needs ring-fenced funding.
- There is no legal right to a Personal Assistance Service in Ireland so the Government needs to prioritise investment in the PAS and enact legislation so disabled people can live a life they choose. See [ILMI PAS campaign](#) to Define a PAS, Legislate, Invest, Standardise and Promote the PAS.

- A specific budgetary commitment is required to meet the cost of and resource the full and timely implementation of '**A Time to Move On from congregated settings**'. Money currently invested in congregated settings should be ring-fenced and invested into appropriate supports for people to live in the community such as PAS or other independent living supports as per our obligations under UNCRPD. Ireland must use its voice at an international level to ensure EU structural funds are not used to institutionalise disabled people. No Irish Aid should be used to institutionalise disabled people and should instead ensure disabled people globally are resourced to live the lives of their choosing.
- Disabled people are often seen as a "risk". Risk assessments and health and safety can be used to preclude disabled people from accessing certain supports or services. For example, some service providers who provide PAS are telling leaders to use two PAs because of the risk involved in assisting them. This should be the decision of the disabled person not the service provider.
- The National Physical and Sensory Disability Database (NPSDD) and the National Intellectual Disability Database (NIDD) do not capture those who acquired their impairments. The databases do not identify the profile of these disabled people and have only captured negligible levels of unmet need. All of the identification of impairments are done with service providers. Disabled people should be at the centre of the process.
- The easy to read version of the capacity review lacks information in relation to a policy context. There should be reference to the UNCRPD as Ireland has obligations under the convention to uphold the rights of disabled people.
- The Disability Capacity Review states that "Participation in day services is virtually lifelong". Disabled people should not be segregated into these services for their entire life and should be given choice as per our obligations under the UNCRPD.
- The review showed that proposed state investment in disabled people's lives for the next ten years, at no point engaged with disabled people about what they want or need to be in control of their lives.

- The proposed investment for day services and residential settings are contrary to disabled people being included in all aspects of social, educational, cultural and economic life as per our obligations under the UNCRPD.
- The Capacity Review is based on continuing to invest in the “Disability Industry” which will perpetuate a situation where many disabled people are segregated from the society. Services such as residential centres, day centres were established in the past by non-disabled people to keep disabled “safe”, to “look after” disabled people. However, these services are often not appropriate for disabled people and they have kept disabled people out of society. This infringes on disabled people’s rights to access the education of their choosing. It also prevents spaces for disabled and non-disabled people to share as equals and ultimately build an inclusive society.
- It is the state’s obligation to put supports in place such as the assisted decision making act and independent living supports so disabled people can decide with who and where they live as per articles 12 and 19 of the UNCRPD to give people choice.
- Independent Living can mean different things for different people. It can mean a good life, a chosen life where people make decisions about their own lives and are supported to have aspirations and goals and a family life. Independent living supports need to be built on the needs of a disabled person. There should be a “menu” of independent living supports where there is autonomous advocacy and self-assessment facilitated so the person can completely have a package of independent living supports or a blend of supports that meets the person’s needs. For example PAS might be a physical support to one individual but it might be an individual to support somebody to make decisions, it might be to accompany someone or it might be a combination of assistive technology (AT) and PAS to attend education or the support might be support to communicate. PAS and independent living supports is not a “one sizes fits all”, it differs from person to person depending on the individual support needs. PAS can be for all disabled people and it should be flexible based on the individual’s physical, emotional, intellectual and sensory needs.

- The state needs to offer supports as our human rights equal to others including a choice for example, if a disabled person wants a qualification or to up skill they should be afforded the same resources to attend that course. For example a disabled student can access supports through the Disability Access Route to Education (DARE) in Universities or colleges, so why can't a disabled person who's accessing post leaving certificate or further education be given supports as well. Disabled people should be afforded a right to a qualification equal to non-disabled people.
- Equality and access proof all funding of essential health services such as BreastCheck, CervicalCheck, and all reproductive health services. Due to accessibility issues and lack of universal design in mainstream services, disabled people often experience poorer access to health and social care services. Disabled women and girls in particular experience barriers to accessing health screening services resulting in lower uptake of breast and cervical cancer screening.
- The "Disability Industry" and the services provided are based on the premise that non-disabled people know best. This needs to stop. Disabled people are experts of lived experience – Nothing About Us Without Us!

Conclusion

The Disability Capacity Review is a comprehensive review of what is currently provided in terms of services to disabled people, how much each of these services cost and detailed projections based on current unmet need and future population growth in the next ten years. The review does not include disabled people themselves and what they need to live true independent lives of choice and control.

Ireland has obligations under the UNCRPD to support the inclusion of disabled people in all aspects of their lives. To move towards fully realising this the government under article 4.3 of the UNCRPD and General Comment 7 must speak directly to Disabled People through their representative DPOs to ensure to invest in what disabled people want and need to participate in society as equals. The “Disability Industry” cannot be part of these discussions as they have vested interest in ensuring investment continues to support the status quo of exclusion and segregation.

This research is welcome but the conclusions it draws are ultimately flawed as at no point are references made to the above national policy commitments to move towards the supports that disabled people want and need to live where they have choice and control over their lives.

ILMI as a National Disabled Persons Organisation (DPO) will engage with its members on this review and may have additional observations going forward.