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

Investment in Inclusion: Resourcing Disabled People to participate in society as equals

Independent Living Movement Ireland submission to the Public consultation on Disability Social Care Services to guide plan for the next 4 years (2022-2025)

Submission summary

ILMI has already published an extensive review of the Disability Capacity Review (<https://ilmi.ie/wp-content/uploads/2021/07/ILMI-overview-of-the-Department-of-Health-Disability-Capacity-Review-July-2021.pdf>). A primary concern was that the review had no consultation directly with disabled people to assess what they wanted. Instead, the review prioritised 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.

ILMI’s submission to the Public consultation on Disability Social Care Services to guide the plan for the next 4 years calls for seven broad principles:

1. Direct consultation with disabled people on a cross-impairment basis with their representative organisations (DPOs) to be prioritised over the Disability

Industry, as per obligations under the UNCRPD such as Article 4.3 and General Comment 7 and Article 29 (b) ⁱ

2. Invest only in services that promote the rights of disabled people to participate in Irish society as equals as per Article 19 of the UNCRPDⁱⁱ.
3. Specifically, whereas 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 per annum to meet the need of disabled people to live independent lives, as per ongoing unrealised obligations under “Towards 2016” to achieving choice and control for disabled people.
4. Recognition that continued investment in segregated services contravenes commitments under the UNCRPD as well as national policy commitments.
5. 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 (less than 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.
6. 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.
7. Disability Social Care Services must invest in supports that promote inclusion in society, specifically models of best practice developed by DPOs like ILMI that can demonstrate value for money approaches to overcoming social isolation and marginalisation, such as our ONSIDE social inclusion project.

Our specific list of recommendations are listed on page 16 of this report.

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 submission 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 submission 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.

ILMI Analysis of Disability Social Care Services to guide the plan for the next 4 years

ILMI as a cross impairment Disabled Persons Organisation (DPO) creates interactive participative spaces for disabled people to lead our policy development. In the development of our “Observations on Ireland’s first draft report to the UN under the Convention on the Rights of Persons with Disabilities” report (<https://ilmi.ie/wp-content/uploads/2021/06/Observations-State-Report-ILMI-April-2021.pdf>) ILMI held ten online consultations with hundreds of disabled people to have them direct and influence our work.

Policy context: International and National Commitments to investment in disabled people to live independent lives and participate in society as equals

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). 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.

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.

Provision of segregated Disability Services and the Department of Health Report of Disability Policy Review

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 (“Report of Disability Policy Review”) 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).”

The “Report of Disability Policy Review” is damning in its assessment of the fact that that services funded by the State to deliver services “to” disabled people are actively undermining the stated policy aims. This confidential Policy Review demonstrates that DPOs are correct in their assertion that segregated services have and will continue to fail disabled people and that they cannot build inclusive communities.

The Policy Review states that the current system “Is based on an incremental model of providing ‘more of the same’ and has not been reviewed in light of increased / improved provision in other settings (e.g. person-centred settings or other mainstream provision)” and is “not based on services achieving policy objectives such as supporting increased independence of service users” (Disability Policy Review p.130).

The Report is stark in the lack of clear data from services about the lives of disabled people or any positive impact and recognises that disabled people who access segregated services have little independence or control:

“There is a very limited amount of information on the quality of life of people using disability services in Ireland. There is also a very limited amount of information on the outcomes for these individuals, that is, what is the effect of the disability services on those who use them? There is a presumption that provision of services leads to better quality of life, but this is not necessarily the case. In fact the available information shows that most of those using disability services do not participate in society in any meaningful way; are not given the opportunity to work or contribute to society. A significant proportion live in segregated settings apart from the general community and live with other people, in some cases many other people (over 4,000 people live in settings with more than 10 beds). **Overall, people using disability services have little opportunity to self-determine or to live full and independent lives.**” (Disability Policy Review p.43).

Whilst the confidential Disability Policy Review outlines the core objective of “Towards 2016” is that people should be supported “to lead full and independent

lives, to participate in work and society and to maximise their potential”, the review recognises that:

“Contrary to the T2016 objectives, many of those using disability services do not participate in society in any meaningful way and many are not given the opportunity to work or contribute to society. **A significant proportion live and spend their days, in segregated settings apart from the general community. Overall, people using disability services have little opportunity to self-determine or to live full and independent lives. The objectives are, nonetheless, still relevant and reflect the thinking in national and international policy documents. However, the realisation of these objectives has not been evident for most people with disabilities.** (Disability Policy Review p.50).

The Disability Capacity Review to 2032

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 over their lives.

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.

More tellingly, the Capacity Review at no stage references the confidential Policy Review which repeatedly highlights how such services undermine the independence of disabled people.

1. 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 full 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, it 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.

Key ILMI recommendation: ILMI would seek an increase to €96 million for Personal Assistance Services (PAS) in Ireland per annum to meet the need of disabled people to live independent lives, as per ongoing unrealised obligations under Towards 2016 to achieving choice and control for disabled people

2. 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 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.

Key ILMI Recommendation: 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.

3. 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”.

Key ILMI recommendation: Given that the HSE and Department of Health have internally recognised that “people using disability services have little opportunity to self-determine or to live full and independent lives”, it is time to move away from these ineffective and inappropriate segregated services and invest in innovative projects that genuinely link disabled people with mainstream services and social inclusion supports (that the Capacity review terms “community connector”). In the last 18 months, our social inclusion project ONSIDE has linked in with 435 disabled people and connected them with social inclusion networks outside of segregated services with huge impact using Zoom and digital skills training. Projects like this impact hugely on disabled people’s wellbeing at a fraction of the cost.

4. 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”.

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.

Key ILMI Recommendation: 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.

Summary Key ILMI recommendations for the implementation of rights based Disability Social Care Services to guide plan for the next 4 years

- 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.
- 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.
- 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.

- 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 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.
- Any 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.
- 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.

ILMI as a National Disabled Persons Organisation (DPO) is looking forward to actively participating to shape the development of a Social Care Service Plan that is based on commitments within the UNCRPD and existing national policy commitments to ensure investment in disabled people’s lives to ensure our full participation in society as equals.

ⁱ **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.

ⁱⁱ **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.