#  Research on the Cost of Disability *Submission to Indecon by the Citizens Information Board*

## Introduction

The Citizens Information Board (CIB) welcomes the fact that the Department of Employment Affairs and Social Protection has commissioned this cost of disability research and appreciates the opportunity afforded to make a submission to Indecon to inform the initial planning phases. CIB would also be available to work closely with Indecon, as suggested, in developing and implementing this significant research project. As the statutory body responsible for supporting the provision of information, advice and advocacy on social services in Ireland, CIB also has a specific remit to provide advocacy supports for people with disabilities. In that context, CIB funds and resources the National Advocacy Service (NAS) to meet the needs of people with disabilities who are in vulnerable situations. NAS has also made a submission in response to this consultation.

CIB has over the years regularly called for a cost of disability payment to help to address the difficulties and challenges faced by people with disabilities in being able to live their lives on an equal basis to the rest of society. We fully recognise that this is a complex area and that a multi-faceted response is required built around a twin approach: (a) enabling more people with disabilities to participate in the labour force; and (b) social protection and supports targeted at mitigating the costs of living with a disability. While these broader matters do not come directly within the scope of the Indecon research, they are relevant in the sense that there is a need to achieve an appropriate balance between empowering and enabling people with disabilities to achieve their potential and ensuring that they are not less favourably treated by society because of their disability.

The submission is set out in two parts. First, some general contextual observations are made which should inform the research approach. Second, the three specific questions identified in the request for submissions from Indecon are addressed.

## General observations

### Disaggregating the population of people with disabilities

CIB wishes to highlight at the outset the need to break out the overall generic grouping *people with disabilities* to more fully comprehend the multi-faceted and very heterogeneous nature of the population being referred to and the related costs of disability. This is required for three reasons:

1. People with disabilities are people first and foremost and their disability is a secondary factor;
2. The label ‘disability’ almost certainly masks the individual attributes of each person;
3. The reality that sometimes may be lost sight of is that, notwithstanding their disability, many people with a disability carry out their lives in a ‘normal’ manner.

In carrying out the research on the cost of disability, it will be necessary to have a clear focus on what is meant by the term ‘disability’. The Disability Act 2005 states that:

 *“ ‘disability’, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment”* (Section 2(1))

Since the nature and level of additional costs associated with disability is likely to relate to some extent to the type of disability, the research should clearly differentiate between categories of disability and different costs associated with different types of disability, e.g., physical and sensory, intellectual disability, Autism, mental health difficulties.

There will be a need for the research to factor in the fact that people with disabilities have different living spaces – in their own homes, living with family, in sheltered/supported accommodation, or in residential care settings. Other considerations will be that some people with disabilities communicate differently (e.g., some are non-verbal) and people with disabilities (like the rest of the population) have different natural support networks.

A life-cycle approach to assessing the costs of disability will be necessary. For example, adapted accommodation provided for a child with a physical disability would need to be reviewed when the child becomes a teenager and again when s/he becomes an adult. Also, the costs associated with disabilities acquired over the life-cycle and as people age must be a consideration.

### Integrating cost of disability research with existing disability-related policies

CIB believes that it is crucially important that the cost of disability research is not carried out in isolation but that it takes into account the various policy initiatives relating to people with disabilities that have been put in pace in recent years. These include, in particular:

*National Disability Inclusion Strategy 2017 – 2021*<http://www.justice.ie/en/JELR/dept-justice-ndi-inclusion-stratgey-booklet.pdf/Files/dept-justice-ndi-inclusion-stratgey-booklet.pdf>

*Comprehensive Employment Strategy for People with Disabilities 2015-2024*<http://www.justice.ie/en/JELR/Comprehensive%20Employment%20Strategy%20for%20People%20with%20Disabilities%20-%20FINAL.pdf>

The *Make Work Pay for People with Disabilities* 2017 report sets out a 10 year approach to ensuring that people with disabilities, who are able to, and want to work, are supported and enabled to do so. <https://assets.gov.ie/10940/c4c20348897148eb9a50ac2755fd680f.pdf> The financial implications of employment for recipients of disability-related payments are outlined in this report and would be relevant to the cost of disability research.

*National Housing Strategy for People with a Disability*<https://www.housing.gov.ie/sites/default/files/migrated-files/en/Publications/DevelopmentandHousing/Housing/FileDownLoad%2C30737%2Cen.pdf>

*Developing a Personalised Budgets approach*A key objective of current Government policy is to explore the concept of personalised budgets for people with disabilities to empower them to live independent lives. The Task Force on Personalised Budgets established for this purpose has published its report.<https://health.gov.ie/wp-content/uploads/2018/07/Task-Force-Report.pdf> and the Government has committed to explore further the concept of personalised budgets through a pilot study.

### Promoting equality of access

Addressing the issue of the cost of disability is linked intrinsically with equality of access. This means acknowledging that while people may differ profoundly in capacity, character and intelligence, the needs of each and every individual are of equal importance and they should have choices in accordance with societal norms and prevailing values. If people cannot participate in society because of additional costs associated with disability, they may also be excluded from taking a real part in the democratic processes of society or from exercising their legal rights. A broad focus on cost of disability is, therefore, required in order to take account all of the aspects of living with a disability, for example, the need for personal assistance to enable people to realise their goals and aspirations, participate in appropriate education/training and work and to engage in social and cultural activities across the life-cycle. For people with disabilities, there are frequently additional costs associated with:

* Maximising capacity and optimising their well-being
* Leading their lives, in a self-determined and autonomous manner
* Asserting their will and preferences in all matters affecting them

The cost of disability research should, therefore, be framed within a human rights and equality framework.

## Specific Consultation Questions

### Background material or research on the cost of disability

CIB has not done any specific research relating to exploring the cost of disability. Clearly, the previous work done in this regard by the Indecon and the NDA will be the starting point for this research. Also, organisations such as Disability Federation of Ireland and Inclusion Ireland have been consistently providing commentary and analysis on the cost of disability issue over the years.

A detailed analysis of the costs of disability which we have looked at for previous submissions and found useful is Cullinan, J. and Lyons, S. (2014), “The Private Economic Costs of Adult Disability” in John Cullinan, Seán Lyons, Brian Nolan (Ed.)*, The Economics of Disability: Insights from Irish Research*. Manchester University Press.

The UK Extra Costs Commission 2015 Report, *Driving down the extra costs disabled people face*, makes a number of recommendations for disability organisations, businesses, regulators and Government to help improve disabled people’s needs as consumers. <https://www.barrowcadbury.org.uk/wp-content/uploads/2015/06/Extra-Costs-Commission-Final-Report.pdf>

Recently published Australian research*, The costs of disability in Australia: a hybrid panel-data examination*, found that the living standard is lower in households with people with a disability compared to households without members with a disability. It also found that current poverty measures fail to consider substantial differences in poverty rates between people with and without a disability. The study considered forgone income due to disability. <https://eprints.usq.edu.au/36265/>

A 2017 paper*, Extra costs of living with a disability: A systematized review and agenda for research,* concluded that costs varied according to the severity of disability, life cycle and household composition. Highest costs were observed among persons with severe disabilities and among persons with disabilities living alone or in small sized households.  This paper also concluded that additional longitudinal data is required as well as more internationally comparable data. <https://www.researchgate.net/publication/316445218_Extra_costs_of_living_with_a_disability_A_systematized_review_and_agenda_for_research>

Implementing the research and facilitating inputs from stakeholders
The following mechanisms should be included:

* Focus groups at regional level (involving people with disabilities, relatives (family carers and parents of children with disabilities) and service providers)
* On site visits to disability residential settings (e.g., meetings with residents’ committees), group homes and day care facilities
* Face-to-face interviews (people with disabilities, family carers and parents of children with disabilities)
* Survey of a general population sample

### Clearly, representative organisations such as Disability Federation of Ireland (DFI) and Inclusion Ireland will have much to contribute to the research as well as disability organisations such as the Irish Wheelchair Association, DeafHear, the Irish Deaf Society and the National Council for the Blind Ireland (NCBI). Organisations such as Family Carers Ireland and the Alzheimer Society should also be consulted. Mental Health Reform, which works to achieve progressive reform of mental health services and supports in Ireland, would be a useful source of information in respect of the additional costs associated with having a mental health difficulty.

Facilitating inputs from people with disabilities and their families will require a strong proactive reaching out and the use of multiple participation forums and channels. Some of these channels will need to be interactive and, for example, be based on approaches such as a Workbook approach based on the concept *Your Voice Matters*  and which enables people to state their experiences through a number of mediums including; written word, drawing and picture illustrations. See, for example, <https://www.hse.ie/eng/services/list/4/disability/newdirections/person-centred%20planning%20framework%20-%20tools%20and%20resources.pdf>

Including the experiences of ‘hard to reach’ groups of people with disabilities and analysing their daily living costs will be a necessary research component. To this end, particular attention will need to be given to those who communicate differently. In 2018 CIB published a research report on *Information provision and access to public and social services for the Deaf Community[[1]](#footnote-1)* which focused on the experiences of the Deaf Community in accessing public and social services and related information on rights and entitlements in Ireland. This report highlighted the fact that members of the Deaf Community have faced severe difficulties in accessing public information in their preferred language which impacts on the realisation of their rights.

There are a number of internet resources which provide guidance on communication with people with cognitive impairment – see, for example, <http://www.bild.org.uk/EasySiteWeb/GatewayLink.aspx?alId=3338>

The Trinity College National Institute for Intellectual Disability would also be a useful resource – see <https://niids.ie/>

The National Advocacy Service (NAS) would be a useful resource in relation to contacting and communicating with people.

In all correspondence and invitations to participate in the research, the purpose and importance of the research needs to be explained very clearly. It should be made very explicit that people are not obliged to participate and that non-participation will have no bearing whatsoever on their social welfare benefits. It is worth noting that this research follows on from other surveys carried out by the DEASP with Disability Allowance recipients – these previous consultations need to be taken into account in designing questionnaires and communicating with this cohort of people.

Specific issues that should be addressed as part of the underlying research on the matter:

Role of income supports
A key research question should be the extent to which existing income support policy does or does not meet the associated costs of disability and the research should have as one of its key components the extent to which social protection measures are effective or not in mitigating the costs of disability. Particular attention should be given to the impact of secondary benefits/supports, e.g., the role of the Supplementary Welfare Allowance (SWA) system, transport subsidies, retention of a Medical Card on taking up employment

Hidden costs of disability
There are items necessary for daily living used exclusively by people with disabilities such as disability aids, home adaptations, therapeutic supports and specialised care services. There are also items used by everyone but which can cost more for a person with a disability, e.g., insurance, specialised clothing and footwear. Also, there are extra costs incurred on items used by everyone but which people with disabilities often use more, such as extra taxi journeys due to a shortage of accessible public transport or extra energy costs because of a greater need to stay warm when not mobile.

Accommodation and household costs
The housing costs relating to disability (e.g., house adaptions, additional heating costs associated with some types of disability, house maintenance) are significant and need to be fully researched. Some of these have been previously highlighted in a Citizens Information Board/Disability Federation of Ireland Report.[[2]](#footnote-2)

#### Transport and access to services

A CIB Report , *Getting There: Transport and Access to Social Services[[3]](#footnote-3)*, highlighted the range of issues experienced by people with disabilities and people with mobility difficulties in relation to travel, transport and access, particularly in rural areas. For many people, a significant cost arises out of shortfalls in the availability of appropriate public transport in both in rural and urban areas resulting in high outlays on taxis. This difficulty is exacerbated for people who do not get a Mobility Allowance from the State (the Mobility Allowance scheme is no longer available to new applicants).

#### Independent living costs

**T**he importance of enabling all people to have the opportunity to have more choice and control over their place of residence and where and with whom they live is central to the cost of living research. This means that people should not be obliged to live in a particular living arrangement. Inherent in this is an acknowledgement that people with disabilities should have the personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community. For many people, the additional costs (over and above what is provided by the State) of buying personal assistance may be very significant and such additional costs need to be fully explored in the research.

Social engagement
In keeping with the principle of normative living based on citizenship and social solidarity, people with disabilities should have appropriate opportunities for holidays, leisure and fun activities and social outings. There is frequently an additional cost incurred in this regard, for example, the need for a companion or PA.

#### Care and support

It is almost certain that people with disabilities who have support and care needs encounter additional costs over and above that which is provided by the State – home help and home care support.

Cost of family care
There is frequently a significant financial cost to families caring for a person with a disability. This can be employment income foregone because of the caring role, payment for additional respite care or the cost of vehicle adaptations.

#### Assistive technology

While it is widely acknowledged that assistive technology has much to offer many people with disabilities and can be a significant factor in enabling independent living, the costs of accessing appropriate technology is prohibitive for many.

#### Healthcare costs

There are frequently additional health-related costs associated with disability, for example, dietary foods, bedding and specialised furniture.

Employment and training
Costs associated with work/training may include personal assistance, travel, dress, lunch, telephone, laptop and, in some instances, costs relating to loss of welfare benefits such as a Medical Card.

#### Support provided by families and friends

The research should also include some reference to the support provided by families and friends which is not paid for but is an essential component in enabling many people with a disability to manage on a day-to-day basis. The Department of Social Protection 2015 Disability Allowance Survey Report noted that family was mentioned by Disability Allowance recipients as the second most important support (after Medical Cards) in helping them to achieve their employment ambitions and goals.[[4]](#footnote-4) See <https://m.welfare.ie/en/Pages/Department-of-Social-Protection-Report-on-Disability-Allowance-Survey-2015.aspx>

####  Indirect cost implications

The cost implications of poor or inappropriate education/training for young people with disabilities which results in poor employment prospects and/or low paid work is a factor which needs to be considered in the research. The lack of availability of suitable part-time work options is also a factor that needs to be looked at – the time-consuming nature of coping with a disability or mental health difficulty can often result in non-availability for full-time work.

#### The episodic nature of some disabilities

There is a need to look at issues relating to the episodic nature of some disabilities. For example, some people get intermittent flare-ups of a physical condition or have mental health issues which prevents them working for a period.  Costs can, therefore, vary for some people at different junctures. This needs to be reflected in the research in order to draw attention to the fact that social welfare disability payments need to show flexibility and be adaptable to changing situations.

### Other issues relevant to the planning stage of the project

There is a need to make a distinction and related comparisons between different types of costs:

* Costs to individuals and costs to households
* Costs to households where there is a child or children with a disability compared to adult households and related to household size
* Costs to the State in relation to welfare benefits, transport and purpose-built housing or adaptations
* Costs to employers in relation to workplace adjustments, including appropriate technology
* Costs to providers of sports, leisure and entertainment facilities
* Cost of living in a residential care setting compared with the cost of living independently in the community with an integrated and comprehensive support package
* The costs that arise because of a person’s physical or cognitive impairment
* The costs associated with mental health difficulties where people are unable to get or retain employment or to have a meaningful social role
* The costs that arise because of deficits in the built environment and communications infrastructure

1. <http://www.citizensinformationboard.ie/downloads/social_policy/Deaf_Community_Research_Rpt_Feb2018.pdf> [↑](#footnote-ref-1)
2. See *The Right Living Space: Housing and Accommodation Needs of People with Disabilities,* <https://www.disability-federation.ie/download/legacy/Full%20Report.pdf> [↑](#footnote-ref-2)
3. <http://www.citizensinformationboard.ie/downloads/social_policy/Getting_There_Report_2010.pdf> [↑](#footnote-ref-3)
4. Other supports mentioned in the survey in order of priority were other social welfare benefits; supportive work environment; access to transport; mental health supports; support from friends; job tasks adapted; flexible hours/work arrangements; Personal Assistance support; access to parking; assistive technology; suitable workplace; adapted work station. [↑](#footnote-ref-4)