

DÁIL ÉIREANN

AN ROGHCHOISTE UM FHORMHAOIRSIÚ BUISÉID

COMMITTEE ON BUDGETARY OVERSIGHT

Dé Máirt, 24 Aibreán 2018

Tuesday, 24 April 2018

Tháinig an Roghchoiste le chéile ag 4 p.m.

The Select Committee met at 4 p.m.

Comhaltaí a bhí i láthair / Members present:

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|--------------------------|--|
| Teachtaí Dála / Deputies | |
| Richard Boyd Barrett, | |
| Thomas P. Broughan, | |
| Joan Burton, | |
| Lisa Chambers, | |
| Barry Cowen, | |
| Michael McGrath, | |
| Jonathan O'Brien. | |

Teachta / Deputy John Lahart sa Chathaoir / in the Chair.

Business of Select Committee

Vice Chairman: Apologies have been received from the Chairman, Deputy Colm Brophy. I will, therefore, chair the session. Today the joint committee will meet representatives of the Irish Wheelchair Association, the Disability Federation of Ireland and Mental Health Ireland. Before doing so, we will go into private session to deal with committee business.

The select committee went into private session at 4.03 p.m. and resumed in public session at 4.08 p.m.

Disability Funding and Disability Proofing Budget 2019: Discussion

Vice Chairman: The purpose of the meeting is to discuss disability funding and disability proofing budget 2019. I remind members and delegates to switch off their mobile phones as interference from them affects the sound quality of the transmission of the proceedings.

I welcome from the Disability Federation of Ireland, DFI, Dr. Joanne McCarthy, senior executive officer, policy and research; from the Irish Wheelchair Association Ms Joan Carthy, national advocacy officer; and from Mental Health Reform Ms Kate Mitchell, senior policy officer. I thank them for making themselves available to meet the select committee and taking the time to prepare material for submission. I also welcome the other delegates in attendance, Ms Joan O'Connor, development manager, and Ms Fiona O'Donovan and Dr. Meredith Raley, policy and research assistants. Our colleague, Senator John Dolan, who is in the Visitors Gallery is also very welcome.

We have received apologies from the Neurological Alliance of Ireland. While representatives of Inclusion Ireland are not in a position to attend, they have provided the select committee with a helpful submission which raises a number of points. We will consider this evidence as part of our work.

Before I invite the delegates to make their opening statements, I draw their attention to the position on privilege which applies to officials who may contribute to the proceedings. Witnesses are protected by absolute privilege in respect of the evidence they are to give to the committee. If, however, they are directed by it to cease giving evidence on a particular matter and continue to do so, they are entitled thereafter only to qualified privilege in respect of their evidence. They are directed that only evidence connected with the subject matter of these proceedings is to be given and asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person or an entity by name or in such a way as to make him, her or it identifiable. Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside the House or an official either by name or in such a way as to make him or her identifiable. We will now move to opening statements. Who will lead us off?

Dr. Joanne McCarthy: I will start. I thank the Vice Chairman and members of the committee for giving us the opportunity to talk to them about this really important issue. All three

of us here are of the view that if the committee can unlock this, it will do a lot to achieve equality for people with disabilities and really change how people with disabilities experience their community services, be they disability-specific or mainstream. We submitted a paper for the committee's consideration. I will not talk to that as it is quite long so I will just pull out some salient points from it. We can come back to anything members wish to address. We also will take the opportunity to notice how timely it is for this to be brought to the committee in light of the recent ratification of the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD, which came into force in Ireland on 19 April. It is really timely that we are beginning to consider this as an issue.

We also acknowledge the work of the National Women's Council of Ireland in this area. I do not think the experience of disability is hugely different to that experienced in terms of gender proofing. While there might be some specifics, the committee has really broken the back of much thinking on this and bringing that to bear on disability would be really helpful. In respect of the key learnings from this work and the work of the Department of Public Expenditure and Reform and others, we want to highlight that any disability proofing of policies or budgets needs to involve different thinking. It is not systemic thinking about one Department and what it does. We would perceive it as something that crosses Departments. We need to think very differently when it comes to people with disabilities. They do not live in silos or just one Department and do not just receive one programme or service. With that in mind, we would say that at the outset, if one is seeking to disability proof in general, one needs to extend across areas. This includes how Departments apply expenditure and how Government first and then public bodies make decisions on expenditure. It includes the information they use to inform what decisions they make, for example, how they are going to use their money and more importantly, that they do not just use this in terms of a systematic look in which they go programme by programme but use a systemic look in which they look across the decisions that any one Department will make and, more importantly, across how one Department's decision has an impact on other decisions made by other Departments. If one takes a step back to consider how budgetary or policy decisions are experienced by people with disabilities, it really helps to understand the jerkiness that can happen if one just engages in systematic thinking.

Moreover, any disability proofing must use disaggregated data. To begin to introduce disability proofing without understanding what data is and is not at hand and what data we want to acquire would be hugely problematic. We also think that good quality and reliable objectives need to govern any decision one might make around how one introduces disability proofing. This includes very strong and measurable key performance indicators, outputs and outcome indicators. I know this sounds quite challenging when it comes to disability. I am sure the committee has heard us and other people in our sector saying there is definitely a data deficit in terms of disability. As some significant work has been happening around key performance indicators and likewise for the national disability strategy implementation group and the value for money process in terms of disability-specific health-related information, there is stuff there upon which we can build.

We know that when these measures are not applied, there can be very poor outcomes in terms of how people with disabilities experience or are affected by policies or procedures. I will give one example. Rebuilding Ireland places a huge emphasis on addressing the social housing needs of the general population in Ireland. We also know that the rental strategy never once touched on or addressed the housing needs of people with disabilities as part of that. We also know that this was despite the fact that in 2010, a report by the Housing Agency specifically highlighted the very specific challenges faced by people we support in terms of accessing

housing. This was despite the fact that we have a national housing strategy for people with disabilities. There is no stitching between the generic housing plans and this strategy, despite the impending ratification of the UNCRPD. One might not necessarily think first and foremost that people with disabilities are one's target audience and one might make budgetary decisions or plan policies without understanding their wider impact on such people. I note, however, that they cross all areas in Ireland and, at 13% of the population, are everywhere. That is an example of why it is important that we are grappling with this issue.

We welcome that this is now on the table. However, we also know that we now have a right. We actually have to do this. There is now a need for us to introduce disability proofing in policy and legislation. Under the Irish Human Rights and Equality Commission Act 2014, all public bodies must take proactive measures to eliminate discrimination against people with disabilities first and foremost. They must also promote equality and protect the human rights of people with disabilities. Even if the committee had not been proactive in beginning to look at how to begin to disability proof, we know there are other pressures that are coming on board in terms of influencing and having an expectation around how policies, procedures and budgets are made with regard to people with disabilities.

We also know that the ratification of the UNCRPD will also pose challenges and ask questions about how we make budgetary decisions and how we begin to plan policies. To return to the point, questions will not be asked in a systematic way but in a systemic way. One will not be told that the answer to our responsibility in respect of the UNCRPD with regard to health will be found only in the Department of Health. If one looks at each article, one will see the interface and interplay that happens across Departments in terms of the responsibility of Departments to answer the need in question. For example, under health, it will not just be the Department of Health that must respond to what is being asked of it in the context of Article 25 of the UNCRPD. The Department of Employment Affairs and Social Protection will also have to respond and think differently about how it will achieve what is being asked of it.

There are significant opportunities and changes taking place, most notably with this committee. The Joint Committees on Health and Employment Affairs and Social Protection have made a really interesting move recently whereby they have indicated that the joint committees will come together to look at how to address the employment and activation issues faced by people with disabilities. That is very significant. The committees are looking at the competing barriers that are being put in place by individual siloed thinking in Departments and are beginning to look at how they can work together to unlock that and offer people with disabilities more seamless access to employment activation and so on. That is the expectation.

We are not alone in this. As the EU has also ratified the UNCRPD, it is also grappling with the need to disability proof its decisions and budgets. We can see some of that coming out in some of its programme work and it is beginning to identify how it needs to include people with disabilities or the needs of people with disabilities in how it applies its budgets.

When the DFI conducts budget analyses, we use a systematic approach. One of the biggest examples of where it became very obvious to us that people with disabilities were inappropriately carrying the burden of the recession was in the context of budget 2012. If members recall, disability allowance for people under the age of 18 was stopped and then there were staged payments for those aged 18 to 25. Other groups were also affected by changes in respect of medical card access and the threshold cut-off point and in the context of educational supports for third level and further education for people with disabilities. When we added up the impact of all of these cuts across Departments, we began to see clearly that the lack of disability proofing

in respect of the budget meant that people with disabilities were carrying a significant burden. This group was already significantly marginalised in Irish society.

We greatly welcome the opportunity to come here today to discuss this matter. The committee asked if we wanted to make recommendations about the budget. We are of the view that we will get other opportunities to do so between now and the introduction of budget 2019. For today, we are happy to highlight the importance of and focus on disability proofing generally. We are happy to answer any questions.

Vice Chairman: I thank Dr. McCarthy and I call on Ms Carthy, national advocacy officer of the Irish Wheelchair Association, IWA, to make her presentation.

Ms Joan Carthy: On behalf of the IWA, I thank the committee for inviting us here today. To follow on from what Dr. McCarthy said, I just want to talk about the impact that disability proofing budgets will have on people.

Disability proofing future budgets is not just of the utmost importance, it is essential for the thousands of Irish citizens with disabilities who want the same rights, choices and opportunities in how they live their lives. People with disabilities did not reap the benefits enjoyed by others during the Celtic tiger years yet they suffered disproportionate, life-changing negative impacts due to the severe cuts applied to the disability sector and health services during the economic downturn. Since 2008, the budget for disability services has been reduced by €136 million. While there was a small increase in last year's budget which brought expenditure up to €1.772 billion, €1 billion has been spent on residential services that only cater for 1.3% of people with disabilities.

Responsibility for disability stretches across all Departments. The IWA calls on the committee to ensure that the Government plays its part in providing fairness and equality for people with disabilities. This means delivering appropriate investment in the personal assistant service, increasing the supply of wheelchair-accessible social housing and funding a fully accessible transport system for all.

For the purposes of this presentation, I would like to concentrate on the personal assistant service, which is the cornerstone, foundation and lifeblood of community services for people with disabilities. This service not only assists with tasks that people with disabilities cannot do for themselves, it also supports people to engage fully in the community, live independently, progress with further education and, for many, take up employment.

It is important to give a real example of how the Government's decisions affect the lives of people with disabilities and, more importantly, to show how a lack of disability proofing has negative impacts. I know of two people with disabilities who have decided to live together with the support of the personal assistant service. This vital service has not only helped them get out of bed in the mornings, it also assists them throughout the day. As one of them said, it gave them the opportunity to be part of society, take up employment and contribute to the workforce and pay taxes. During the years of austerity budgets, the couple were informed that their personal assistant hours would be cut and that they would have to manage with a skeleton service of basic hours that would barely cover the time needs relating to personal care. The impact of the reduction meant they were faced with having to cut back their working hours and reduce much needed therapies. They also could not even consider socialising of any description. Is this any way for people to live? Is it not terrible to build an independent life for oneself and actively live in an inclusive society only for it to be taken away because funding for vital dis-

ability services is not seen as a priority, and to not have a voice in Government and no system of protection? There is a problem with the way the Government sees or understands what is meant by a personal assistant service. The service is not a home help service or a care package. In fact, it is a way of life that enables persons with disabilities to do all the things that the members here, who are their peers, take for granted.

Without disability proofing, the HSE has stretched hours in the personal assistant service due to a chronic lack of investment. For example, a person with a disability has a care package of 64 hours. If he or she dies, then his or her hours, which were previously assigned to one person, are reallocated across five or six people. This means that the individuals receive a totally inappropriate service that does not meet their requirements.

There are figures that tell us about the amount of personal assistant hours provided but, unfortunately, there are no figures that reflect the scale of the unmet need for people who require such services. The lack of such vital information makes it impossible for the Government to plan or fund an appropriate service. Ireland has an ageing population and, therefore, more people will be reported as having disabilities. People who have disabilities and who already have services in place are living longer and will require extra support in the coming years. Does the Government have a plan for such an inevitability? Plans are in place for other sectors.

The Government needs to disability proof future budgets and ensure that the unmet needs of people with disabilities are catered for. Vital services cannot be cut as a result of the lack of understanding of the true value of a personal assistant service to a person with a disability. The value-for-money policy is based on people being moved into the community but the Government has continued to cut the only community enabling service, namely, that relating to personal assistants, currently in operation. Decongregation, new models of day services, etc., are all based on high functioning personal assistant services. There is a need for an extra 500,000 personal assistance hours to be injected into the system to cater for those people who receive inappropriate services. This would cost €12.5 million.

We strongly encourage members to consider the long-term, positive impacts investment in this sector and the service will have on the Exchequer. We suggest that a standing committee or office be put in place in order to oversee the disability proofing of budgets and all policies.

Vice Chairman: I thank Ms Carthy. I call Ms Mitchell, senior policy and research officer with Mental Health Reform, to make her presentation.

Ms Kate Mitchell: I thank the Chairman and committee members for inviting Mental Health Reform to appear this afternoon.

Mental Health Reform is the national coalition on mental health in Ireland. It comprises 64 member organisations. We advocate for improved mental health services and the social inclusion of people with mental health difficulties. We very much welcome the opportunity to discuss the national mental health budget, in addition to issues of transparency and accountability in mental health funding and expenditure.

I shall touch on four key issues: the continued under-resourcing of mental health services in annual budgets; the absence of a national mental health information system and, consequently, a lack of reporting on mental health expenditure; the potential impact of the recent HSE restructuring on the mental health budget; and the requirement to proof budgets in the context of mental health.

First, with respect to the continued lack of funding for mental health services, the total budget for mental health services in 2018 was just €912 million. If fully realised, this level of expenditure will equate to just 6% of the overall health budget. This proportion represents a reduction on previous years and severely lags behind in terms of national and international standards. It is imperative that mental health is recognised and afforded appropriate priority within the wider health agenda in order to reflect its significance in contributing to the burden of disease in Ireland. This will require a substantial increase in mental health funding to sustain existing levels of service and facilitate the development of new mental health services and supports, a matter which has received little or no attention to date.

In addition to the continued under-resourcing of the mental health system, there is no national mental health information system - supported by key performance indicators - to report on the full extent of service resources, provision, quality and outcomes for community-based mental health service delivery.

Mental Health Reform has been calling for a such a system in budget submissions since 2013. It is not acceptable that more than 12 years after publication of A Vision for Change, there is no information system to account for the more than €800 million to €900 million in public expenditure on mental health care each year.

On HSE structure, there has been substantial reorganisation of management of mental health services since the publication of A Vision for Change including the appointment of a national director for mental health in 2013 with overall responsibility for a distinct mental health budget and delivery of mental health services. Further restructuring of governance and accountability structures in the HSE in 2018 has led to the dissolution of the HSE's mental health division and national director of mental health position. It is vital that coherent leadership in mental health at national level is not lost in the new HSE structure and that there is clear authority and accountability for a distinct national mental health budget each year.

Aside from the moral and social implications, there is a strong economic basis for investment in mental health services. The World Health Organization, WHO, recognises that mental health influences a wide range of outcomes for individuals and communities. It is both a cause and a consequence of social and economic status. The WHO further identifies that in order to improve the mental health outcomes of the population, the Government must focus on facilitating a mental health in all policies approach in which "policy makers across all sectors think in terms of mental health impact". Such an approach should also be applied in the context of mental health proofing of budgets. Ultimately, this means taking account of the mental health impact of budgetary decisions on the population, including individuals with existing mental health difficulties, across a multitude of areas, such as social protection, housing, employment, education, and early years.

Given the scale of money involved in mental health, the lack of transparency about how mental health funding is spent and considering the lack of systems in place to track and support this spending, our specific appeal to the committee today is it takes on accountability in mental health funding and expenditure as an immediate priority in budgetary oversight.

Vice Chairman: I thank Ms Mitchell and call on Deputy Jonathan O'Brien. He has a few minutes. If the witnesses care to answer immediately rather than waiting until the end, they should feel free.

Deputy Jonathan O'Brien: I thank the witnesses for their presentations. We have a legal

obligation to ensure our budgets are equality proofed.

Dr. McCarthy referred to the importance of data. What type of data currently exist and where are the gaps? For instance, one area where I have been trying to secure information is that of the private rental sector, to which Dr. McCarthy referred. I have not been able to get a number on how many properties comply with the Part M regulations. If we do not have that type of data, how can we plan for demographic changes and so on? Will Dr. McCarthy comment on the data, its importance and what we can do to improve that?

Related to the same issue, Ms Carthy said that the Irish Wheelchair Association was looking for 10% of all future builds to not only comply with the Part M regulation but to be accessible for people in wheelchairs to live, not just to visit. Will she comment on that? It may be a silly question, but can she differentiate between what the Part M regulations envisage with regard to visitation as opposed to having a property in which someone could live?

On the process and how we move it forward, lessons are being learned from gender proofing; if the witnesses were setting the indicators, what type of indicators would they seek in each Department? It goes right across the Departments, even article 28 covers about five different Departments. It is not good enough for one Department to set indicators, it needs to come out of the silos, as Ms Carthy put it.

On the Department of Justice and Equality having issued guidelines for Departments and how to conduct a disability impact assessment in 2012, can the witnesses say how well it is working or is it working?

Dr. Joanne McCarthy: On the data deficit, there were two databases in place on disability, housed under the Health Research Board, HRB, which have recently been amalgamated into a single database. One was physical sensory-neurological and the other was intellectual disability. It is commonly held that the intellectual disability database probably captures the health needs in terms of planning for services well enough; these would often mean disability-specific services. Also, because of the voluntary nature of the enrolment, there is a huge problem in the physical, sensory and neurological data. Resources were put into the HSE to support the ongoing enrolment in physical, sensory and neurological but that fell away. The data in that area is not reliable.

The data on intellectual disability is reliable but one has to ask what kind of questions are being asked. The questions one asks brings about certain answers. That is where most of the disability data is being housed.

The Disability Act was never enacted nor was the assessment of need beyond a certain age on children. That had the potential to be a great source of information in identifying the levels of unmet need for people with disabilities generally. As that has not been enacted, that information is missing. Deputy O'Brien is correct that there is a significant deficit in the data being captured on people with disabilities. The personal assistant service, PA, is a perfect example. For those who are familiar with the Disability Federation of Ireland, DFI, we usually brand our work around supporting people to participate in the community, we are about enabling individuals and communities for people to participate and be equal citizens. We see, as would the Irish Wheelchair Association, PA as being the cornerstone for that because it enables and supports people out into work, socialising, the gym, and all the things that we take for granted. However, there has been no systematic data gathering around the level of unmet need on PA. It is very hard to plan for a service when the level of need is not fully appreciated. The identification of

real data which is tangible and can be built upon would be hugely beneficial.

Ms Kate Mitchell: I will address two of Deputy O'Brien's questions.

On data and the types of indicators which we should develop, I completely agree with Dr. McCarthy that there is a huge deficit in data collection and research. That spans the mental health system. For example, in primary care we have very little information on the numbers of people presenting to primary care settings with mental health difficulties, the types of mental health difficulties they are presenting with, or the types of care and treatment that they are receiving. One of the biggest issues we have with the lack of data in the mental health services is that we have no national information system whatever, which was a recommendation in A Vision for Change. As far back as 2007, a number of national and international economists recommended this very strongly, but we are still in the same position. We should have very basic information such as detailed data on expenditure, where money is going, staffing and the quality of service people receive. One of the questions in that regard relates to how many people using mental health services are offered psychological therapy and how long are they obliged to wait. We do not have that information. We have absolutely no information on outcomes for people with mental health difficulties using the services, such as how many enter employment or how many are in secure housing. Those are the types of indicators we should be developing as the basis for an information system.

A Vision for Change is a very strong policy document that is still relevant but it did not discuss gender mainstreaming in the mental health services and did not provide any guidance in that area. That should be addressed in the current review of A Vision for Change.

Ms Joan Carthy: In respect of housing, the part M regulations refer to accommodation being visitable. In other words, a person can visit their friend or cousin, the front door is wider, the entrance is flat and there should be a downstairs bathroom, which is usually never accessible because it is under the stairs. We are looking for accommodation to be liveable such that a person can get a house through social housing or privately that they can live in because it is wheelchair accessible. It would have downstairs bathroom facilities - an accessible bathroom. It is based on the needs of people with disabilities living in the community. When the housing needs analysis was done there were over 4,000 people with disabilities on the housing list. They were seen as being the biggest single group of people with a need for housing.

Deputy Jonathan O'Brien: I suppose Ms Carthy does not know how many such houses there are in the private rental sector.

Ms Joan Carthy: No. We are trying to get some sort of information on that, even to see what developments are being planned for either social or private housing and how many will be wheelchair accessible. We cannot get that figure.

Deputy Lisa Chambers: I thank the witnesses for their presentations. I am working with a girl with whom I went to school who had a very bad cycling accident when she was 27 and is now quadriplegic. Her story is in the public domain. She has given interviews to several newspapers. She has been waiting four years to get a care package but it has not come through. She is from Mayo. She lives in a congregated setting in Sligo and cannot get out of it. I am working with Mayo and Sligo county councils on the matter and public representatives from across the political divide are trying to resolve it. We have been interacting with the different services for probably two and a half years. The HSE has been abysmal in dealing with this. Ms McCarthy said that when one person no longer needs the hours, they are divvied up between

five or six people. I gather Geraldine – I do not think she will mind me giving her name as it has already been made public - is on a waiting list indefinitely until somebody no longer needs a care package and she gets to use it. That is the kind of response I get. The local authorities said they could not get housing for her until the care package was in place. It is a chicken-and-egg situation.

I have met both local authorities, as have Geraldine and her team, but we are no further along. We have a ream of paper but no solution. I have done searches on *daft.ie*, as have Geraldine and others, for properties to purchase in order to see what is being built. There are two projects that have come through the planning process but it will be two years before they will be turnkey ready. They are quite far out of the town so they are accessible but not inclusive. How is she to live if she cannot get from her home to her place of work? Thankfully, other factors are working out better than the accommodation. Have the witnesses any suggestions on how to deal with the housing issue or what has their experience been? What do we need to do to get a budget to deal with this? I feel the local authorities would like to do more but one commented that they do not want to be competing in the private market and purchasing properties because they will then drive up the price for other buyers at a time when there is very little housing. That does not help the person looking for the home. I do not know where we will go from here. We are still going back and forth.

Do the witnesses have any suggestions about the care package? Is it simply a case that there are not enough to go around? The personal assistant service is the same. I could not agree more with the witness. People are not being given the choice between the service, home help hours or care packages. They are being told they are getting X number of hours in a particular context and that is it. They might say they would like fewer home help hours and more personal assistant hours because they want to get out and have a coffee or to go to a play or something. The choice does not seem to be there.

Have the witnesses seen what other countries have done in their budgetary processes to proof disability inequality? What are their top two suggestions for what we could implement as disability proofing in budget 2019?

Dr. Joanne McCarthy: Our understanding of housing is that guidelines were issued last October to the effect that they could not block assessments or allocations because there were not enough personal social service resources required to enable the person. It may be worthwhile going that way. For the medium term, there are personalised budgets. The task force on personalised budgets has just completed its work and that report is now with the Minister of State with responsibility for disability. There will be a commitment to piloting, for want of a better word, models of personalised budgets. Geraldine could perhaps ask if hers could be one of the pilot cases.

There is a huge inequity in the experience of disability services depending on the disability. Someone born with a disability is included in a cradle to grave approach, a wraparound concept of services. If a person acquires a disability as he or she ages it is much harder to access disability services. It should not be that way. The existing service models soak up between 80% and 90% of the budget. Planning for unmet needs if a person's experience of disability changes is not incorporated into the planning and delivery of existing services.

Ms Joan Carthy: On housing and the connection with the personal assistance services, there are all sorts of policies and strategies already in place but there is no stitching between the mainstream strategies and those for people with disabilities. The work has been done on the

strategies but it is down to implementation and putting in place the proper amount of funding. Over and over we hear this same problem about somebody who needs housing and personal assistant services, one cannot come without the other. The HSE says in emergency circumstances it will put this funding in place but the person needs to have the house first, to have a permanent address. The two Departments are not coming together to figure out the best way to put a service in place for an individual. People are fighting over and over for services and that is wasting funding because of the professionals who get involved. That in itself is wasting funding because of the professionals who get involved in this piece of work. It is about Departments working together to identify what the need of the individual is, not working constantly in a silo.

Dr. Joanne McCarthy: It is also about planning newer models of service. In this case people are looking for support packages that will enable them to continue to live independently in the community. We are carrying out research in Disability Federation Ireland on about 1,000 people under 65 years who have been inappropriately placed in nursing homes. Although they are predominantly residences for older people, because there is nothing else available in the system, they have been placed in them. That should not be the case. There should be a raft of community supports and services, whether it be for someone with an acquired brain injury or someone under 65 years suffering from early-onset dementia. There should be other options and packages available. It also depends on demographics and data, about which someone asked earlier. We are not planning in a way that is in keeping with the demographics. We may not know the exact person who will have an acquired brain injury, but we know what the trends are across Europe and they are steady. We should be able to use the data to inform our planning as opposed to waiting and reacting to priority issues.

Ms Kate Mitchell: On the housing issue, the Housing Agency has been doing a lot of work in this area, particularly in the past couple of years. Linked with what Ms Carthy and Dr. McCarthy have been saying, one of the really important measures that has been taken is an analysis of housing need and future needs. Local authorities have been doing a lot more work in collecting data. It will be very interesting to keep an eye on that space.

Something that also seems to have been working effectively is having liaison points between the local authorities and disability and mental health services. The liaison officers are very aware of housing needs in their areas, the individuals who require housing and the particular things that need to be taken into account in making adaptations and so on. However, there is also a requirement for training of local authority staff. The individuals on the front line who are making assessments and allocation decisions need to be appropriately aware and trained in how to deal with disability and mental health issues. There is much greater co-ordination between local authorities and disability and mental health services in that regard.

On proofing and the position in other jurisdictions, there are other jurisdictions where mental health services are allocated funding at a much higher rate as a proportion of the total health budget. In England and Canada it is at a proportion of about 13% and in New Zealand about 11%. In Ireland we are at a figure of just 6% and that proportion has decreased during the years. That issue certainly needs to be looked at as a priority. In other jurisdictions they are also investing very much at the early stages. They are seeing great returns on funding where they invest in the early years in perinatal mental health services.

Deputy Thomas P. Broughan: I welcome our guests and thank them for some very informative papers on disabilities and disability services funding. Did they carry out any analysis of budget 2018 and the decisions made in it? How are those decisions playing out during the current year? The delegates mentioned the Parliamentary Budget Office. What role would

they like to see the office fulfilling in the disability proofing of budgets? Have they been in contact with the director or any of the staff in the office to get them to work on the additional data that might be required? In respect of the Department of Public Expenditure and Reform's programme on gender equality budgeting, would the delegates like to see a similar programme emerging for the disability proofing of budgets?

On costings, I noticed that several of the presentations were looking forward to 2019 and up to 2021. As Ms Carthy said, the personal assistant service is at the heart of some of the resources we need. She mentioned a figure of 500,000 hours. There was also a reference to the personal independence payment which has been introduced in the United Kingdom. What is the delegates' attitude to it? A costed disability payment was mentioned. I remember proposing such a payment with other colleagues 15 or 20 years ago. The suggestion has been made during the years. What costings have the delegates made for 2019 onwards?

Dr. Joanne McCarthy: I will pick up on the programme of the Department of Public Expenditure and Reform. It is a really interesting pilot programme. There is a responsibility to equality proof. There is also more information on gender and greater clarity on the issues involved. Six Departments decided to play ball and identify areas they would highlight in respect of gender proofing. This has to be applauded. The initiative came up in a previous hearing. I also agree that they may not have been very ambitious in terms of the programmes that were to be tested. Perhaps we might look to bring greater ambition to the process if we were to disability proof. There was a lot of work done on indicators. We have a national disability strategy implementation plan. The detail is slightly outdated in the light of the UN Convention on the Rights of Persons with Disabilities, UNCPRD, but the high level goals are still in place. We would have to look at strengthening the indicators in order that they would be more ambitious in the outcomes to be achieved for people with disabilities. My answer to the Deputy is that it was a good attempt, but for our sector, we would like it to be more ambitious and would much prefer to see a more systemic analysis, testing how Departments are working across each other to support people in having really good lives in the community.

Ms Joan Carthy: To pick up on the question about the Parliamentary Budget Office or somebody overseeing this piece of work, whatever disability proofing needs to be done, or if there is to be work done on the data and unmet needs, there does need to be somebody in a position to oversee it. Such a person would be able to ensure all Departments were being pulled in in order that it would not end up falling within the remit of one Department. That needs an overseer. I hope that would help to produce the information we require.

On the key indicators, even at this level, it is a matter of looking at the unmet needs and the data. They should be a starting point for the key performance indicators even before we get to measure the impact on people with disabilities. We should include how we will gather the information we require as part of the KPIs.

Ms Kate Mitchell: To answer the Deputy's first question, we responded soon after the budget for 2018 had been announced and had some very serious concerns about the mental health services budget allocation to maintain existing levels of service. The HSE has been very clear in its most recent operational plan that, owing to demographic changes, national pay agreements and various other factors, it will struggle to maintain existing levels of service within existing budgets and also struggle in the development of new services. Development funding was allocated to the mental health sector in recent years to invest in new services that had been recommended in A Vision for Change. We had a concern about the amount allocated and it was increased a little subsequently following liaison with Ministers. The Minister, Deputy Simon

Harris, and the Minister of State, Deputy Jim Daly, have committed to significant investment in mental health services in 2019 through the provision of €55 million in development funds. It is imperative that commitment be fulfilled.

On the role of the Parliamentary Budget Office, I mentioned that there was a massive issue in the mental health area in that there was no national information system. A key role for the committee and the office would be in the provision of a direction and the oversight of budgetary decisions on mental health service funding and expenditure.

Deputy Joan Burton: I thank each of the delegates for providing us with such interesting and comprehensive presentations. I have a specific question. It is a small one, but it arises a good deal.

Growing children who are wheelchair users and perhaps have very severe disabilities, both physical and intellectual, often experience a long delay in being given a new wheelchair which may also be more advanced. Do the delegates have views on how families could be assisted in that regard? It is an important matter for them when they have a child living at home as he or she grows to become a teenager and an adult. Do the delegates have ideas on how that issue might be addressed better? Certainly in my area, it can take a long time for someone to be given a new wheelchair.

We have quotas for the employment of people with disabilities, particularly young people who may have a physical disability, be highly qualified and are anxious to find employment. Do the delegates consider the quotas to be adequate? Do they consider they should be applied to larger places of employment in the private sector, as well as the public sector? There are many bright people who have a physical disability but whose employment opportunities are heavily restricted simply because they do not even get to interview stage. The Dublin Institute of Technology has taken a number of initiatives with a number of employers, but we do not have scale in the way other countries do. Do the delegates have proposals in that regard?

When I was in office, I spent much of my time encouraging the recreation of apprenticeships in Ireland, both new apprenticeships and, in particular, traditional apprenticeships which fell away in the financial collapse. I asked employers, both in the public and private sector, about providing apprenticeships for people with disabilities which, unlike in other countries, do not feature very much on the radar. Has any progress being made in that regard?

Regarding Ms Joan Carthy's comments on the personal assistant service, I was involved when the Centre for Independent Living was established many years ago. The first allocation of funding came from the then Department of Social Welfare. Do the delegates have views on where services should be located? Would it be better if over a period of time, they were moved to the Department of Employment Affairs and Social Protection as in that way they would be part of income and life support, as opposed to medical support? It is not about people with disabilities being ill but about having a condition in respect of which they require support. I often felt like giving up on some of the detail in the Department of Health.

Vice Chairman: I remind the Deputy of the time allocation.

Deputy Joan Burton: I have one further question. On the issue of income support, obviously, in the Department of Employment Affairs and Social Protection it is accepted as such. With respect to younger people, particularly those with mental health issues, what are the delegates' experiences in their being able to access income support and subsequently being able,

as they choose to do on a voluntary basis, to access help and support through a community employment scheme? How do the delegates see it progressing?

Vice Chairman: Ms Kate Mitchell might respond first.

Ms Kate Mitchell: In accessing income support people with mental health difficulties, including young people, have reported a number of difficulties, including in liaising with staff in the Department of Employment Affairs and Social Protection. They often cannot access an advocate or bring one along with them to address some of the issues related to income support. That is a significant issue.

People with mental health difficulties have the highest rates of unemployment in comparison with any other disability group. More than 50% of participants in a recent study which was the subject of a report on disability allowance by the Department of Employment Affairs and Social Protection reported mental health difficulties as being the reason they were in receipt of disability allowance. A few issues arise in that regard. For people with severe and sometimes enduring mental health difficulties, existing support and employment structures have not been successful in supporting them into employment. The Government is looking at the provision of individual placement support which is the international evidence based approach to supporting individuals into employment and which has proven to be very effective in other jurisdictions, including the United Kingdom, France and Australia. For individuals on the more moderate scale of mental health difficulties, there is more flexibility in supporting them to enter employment and sustaining them in it. These supports are available within the work environment to ensure they do not fall out of work or, if they do, that they can be supported back into work quickly.

Ms Joan Carthy: To pick up on the issue of employment, in this instance it is important to have quotas. They need to be brought forward in the private sector also. Account needs to be taken of the services that assist people into employment. It could involve the personal assistant service, the provision of a medical card, transport and so on. Like any other issue that comes up, employment requires a cross-departmental approach. There needs to be greater awareness across the private sector of the ability of people with disabilities and their untapped talent. Account also needs to be taken of all of the other services that need to be put in place for some people to help them get back into employment.

To respond to the question about the assessment of need for young children who need new equipment as they grow, that happens across the board, whether it be for a young or an older person who needs extra services or equipment. It comes down to a lack of funding. There is no magic wand, other than carrying out of an appropriate and timely assessment and funding being put in place to enable the equipment to be made available to the individual concerned.

Dr. Joan McCarthy: To build on what my colleagues have said, quotas were always the poisoned chalice. We want them because we want to give people good opportunities to find employment, but they are definitely not high enough. We were not ambitious enough when we put them in place, even within the public sector. The other problem in that we do not track and often people go in at entry level and get stuck there. There are some basic issues with courses which we need to address before we even begin to look at broadening this and making it the responsibility of the private sector. We need to figure out where it is currently at and then use that information to go further. The private sector does have a role to play around employment and supporting people with disabilities into employment. This is about the incentives and supports that we put in place to enable employers in the private sector to feel confident and comfortable

around employing people with disabilities. We need to learn from the courses in place and why they are not working.

On which Department is best placed to work alongside the Department of Employment Affairs and Social Protection, the Disability Federation of Ireland, DFI, would like that to be the Department of the Taoiseach. We feel it is our time. The existing national disability strategy is 12 years old and it was hammered throughout the recession and is way behind where it should be. We believe the Department of the Taoiseach now needs to row in behind this strategy. In terms of a systemic approach, only the Taoiseach's office can demand that Departments work together. The view within the disabilities sector is that the Department of Employment Affairs and Social Protection should be the lead Department because it is about the lived experience and day-to-day issues such as income, employment and so on but that no one Department can resolve disability issues. In transferring responsibility from the Department of Health to the Department of Employment Affairs and Social Protection we might be repeating the same experiences we have had to date in terms of the latter being able to answer everything. If that is the case, that is not the answer. What we need is an implementation plan led by two or three Departments. The initiative taken by another committee - whereby the Departments of Health, Employment Affairs and Social Protection and Education and Skills have come together, in terms of dealing with a person's health to see what he or she requires in terms of personal social services or to enable him or her to go on to further education and then on to employment, and in terms of income - is interesting. We all know the additional costs associated with having a disability. This type of interface between Departments would enable people to be equal and active.

Deputy Richard Boyd Barrett: I thank all of the delegations for their informative contributions to the committee. What I heard loud and clear from all them is that we need to rid ourselves of the silos and to ensure interconnectedness between Departments on disability issues. Dr. McCarthy suggested that the Department of the Taoiseach should be the link Department, which is a straightforward request we can make. It makes sense.

On the lack of personal assistant supports and mental health services, is the biggest problem in terms of getting additional personal assistant hours a resistance to allocating bigger budgets or is there also recruitment issues? I have heard through my colleague Deputy Gino Kenny that in mental health services, recruiting and retaining staff is a huge problem. What do we need to do in this space and what are the budgetary implications of trying to address the problem of recruiting staff in these areas? We hear a lot from the Government now that money is not an object yet, it appears, services remain unable to recruit staff. Something is an obstacle. Is it that the pay and conditions for the people we need to recruit in these areas are not what they should be and, consequently, people do not work in them or there is a high staff turnover? I would welcome a comment on this issue.

I am struck by the comments on the housing issue. I am concerned for all sorts of reasons, as are many others, about the over dependence of the Government's Rebuilding Ireland strategy on the private sector, primarily because I do not think it is capable of delivering. It was mentioned that we also cannot depend on the private sector to provide accessible accommodation. Perhaps the witnesses would elaborate on that point and also on the fact that there is no requirement on private developers to ensure a percentage of its housing is accessible housing, which is clearly something we should be pushing for.

It was mentioned that medical cards are granted based on people's needs and the high cost of prescriptions and so on. On transport, is free travel for people with disabilities an issue? Senator Dlolan's office recently contacted my office about a lady in my area who is non-verbal

and was issued a fine for not having a valid parking ticket, which was later quashed following intervention by Senator Dolan's office. As I turned out, I knew the person. I could not believe this happened. This lady cannot get a free travel pass for public transport. Is automatic entitlement to free travel for people with disabilities an ask of the Disability Federation of Ireland?

Vice Chairman: That is very unfair.

Deputy Richard Boyd Barrett: It is really unfair. As far as I am concerned, it is bonkers. Perhaps the witnesses would comment. I think the issue for this lady is that she is not eligible for a free travel pass because she is not in receipt of a disability payment, which is crazy. That she was issued with a fine is also crazy.

Vice Chairman: We all have constituents who have had similar experiences. A constituent of mine who lost most of one of her arms is not eligible for a disabilities parking permit, which is bizarre. The case is currently with the Office of the Ombudsman.

Deputy Richard Boyd Barrett: My final question is about the lack of consistency at DART stations in terms of accessibility, advance notice of travel requirements in relation to access and the removal of personnel who assist in that regard from some of the DART stations. Perhaps the witnesses would also comment on this issue.

Ms Joan Carthy: I will respond to the questions on personal assistants and the DART service. On the personal assistants service, PAS, there is a resistance to funding the service. On the employment of personal assistants, there is need for a review of what people are earning and how we can entice people into the service. From the Irish Wheelchair Association's point of view, a large number of our personal assistants are on low contracts and, with additional funding, they would be able to take on more hours. These are the people we need. There is a problem with taking in other people. There is also a problem relating to people who are on social welfare. If they try to come from social welfare to work in a personal assistance service, as we can only take people on for a low number of hours due to the lack of funding for services, they cannot give up their social welfare payment. They are caught in that position where they cannot come away from jobseeker's allowance or such to take up work because we do not have the extra funding. It is a catch-22 situation. Another issue relates to pay restoration and the funding that should be coming down the track to pay for the personal assistants who received wage cuts. That has not been restored and is an issue. There are people working for the Irish Wheelchair Association, IWA, and other services who could easily take on more hours if the funding is provided.

There is a report from the Department of Transport, Tourism and Sport relating to the pilot project launched for the DART in late January and early February. The report looks positive but a big part of the problem is that people find it difficult to report when things go wrong on Irish Rail's website. People with disabilities are not really that great for putting in those complaints. I do not think it will be a real reflection of what is happening. As part of the pilot project, the 24 hour notice period was reduced to four hours but staff have been taken out of the stations and stations have been hubbed, so one person might cover four stations, and one still has to ring and hopefully somebody will be there. What happens, more often than not, is that somebody might be there to get a person on to the DART but there might not be somebody at the other end to get a person off, which in itself is a huge problem. A couple of organisations came together to push that with Irish Rail. We are keeping an eye on the reports and on our own members and any issues they have so that we can report back separately to Irish Rail's report.

Dr. Joanne McCarthy: I will pick up on the pay and conditions issue and reiterate some points. There is also the ongoing issue with the differences between section 38 and section 39 bodies. I am sure the Deputy is aware of that and the impact it is having. We know that there is a process under way that is looking at just that. It is definitely an issue of how we employ and retain staff. Do not forget that we invest in training and supports and want to build a healthy pool of staff that can support and enable people with disabilities. If one cannot retain staff, that is hugely problematic and very unsettling for people with disabilities who are dependent on a very personal relationship and often intimate care. It is hugely unsettling for them if we cannot sort this out so that they can be confident about their access to services going forward.

On housing, we all know that it is meant to be based on the disability steering group's input and the assessment of social housing needs. That is supposed to be happening from local authority to local authority but it is not. This has been identified and the Housing Agency is looking at this going forward.

Ms Kate Mitchell: I will pick up on the Deputy's question about staffing in mental health services. He is correct that there are massive challenges with recruitment and retention in mental health services. In general adult services, we only have about 75% of what is required, and the situation is much more dire in child and adolescent mental health services, with only about 51% of the required staff in post. That has massive implications for staff and for people and families accessing services, with waiting times, quality of services and so on. Pay and conditions are an issue. It is difficult for Ireland to keep pace and to compete with other jurisdictions such as Canada, Australia and even the UK. We see many of our graduates moving to other jurisdictions to work in the mental health space. The conditions are also an issue. We regularly hear from professionals that they do not want to commit to work in a service where they know they will not have the full complement of staffing. There are also issues relating to promotional opportunities. It is an issue that extends beyond the HSE and Department of Health to the Department of Public Expenditure and Reform. We need to look at pay and conditions in mental health services. Mental Health Reform has advocated for a new way of thinking and a new way of looking at service delivery for quite some time. There has been a strong emphasis for a long time on the recruitment of medical staff, nurses and psychiatrists. There needs to be more of an emphasis on recruitment for other disciplines such as occupational therapists, psychologists and social care workers. There is also an emphasis on the community and voluntary sector. They play a fundamental role and there is space for investment in that area and for peer-led community mental health services.

Deputy Richard Boyd Barrett: Can I ask one last question? It is very short. I forgot about it with the initial questions. When refugees come into the country, do the witnesses keep an eye on the extent to which, as part of our refugee resettlement and acceptance programmes, we try to assist people with disabilities? I ask because I am dealing with a family from Gaza who are in Turkey. Four of them are severely disabled. They cannot go back to Gaza, for obvious reasons, and are stranded in Turkey. I am trying to see if I can help them to resettle here. Is there any focus on that? I suppose the Departments of Foreign Affairs and Trade and Justice and Equality deal with that. Do we ensure that we help people with disabilities who are looking to come into the country through resettlement or otherwise?

Ms Joan Carthy: From the IWA's point of view as a service provider, if we were informed of a family that had got this far, we would provide the services we would provide to anybody else. On a bigger policy piece or us reaching out in some way, that is not happening. I do not know whether it is happening on a wider basis.

Ms Kate Mitchell: On the mental health side, there is an obligation for Ireland to provide mental health services to all members of the community. That includes people from ethnic minority groups, including refugees. There are significant barriers there with regard to help-seeking behaviours among people from ethnic minority groups, language barriers, and being able to access appropriate and culturally sensitive services. There is a question of whether we are delivering culturally sensitive mental health services and to what extent. There is a significant amount of work to do in that area.

Dr. Joanne McCarthy: The Disability Federation of Ireland, DFI, knows across the organisation that there is an issue. For example, I know of what was previously called the Post Polio Support Group. As we know, polio has almost been fully eradicated except for those currently living with it but it is resurgent now because of people coming into Ireland with polio. The organisation has to rethink the services and supports it offers. I support my colleagues in saying that service-providing organisations definitely feel those issues on the front line. We work with a Dóchas working group on policy. I ask the select committee to contact us if it would like further information on the interesting work we do with Dóchas.

Vice Chairman: On behalf of the select committee, I thank Dr. McCarthy, Ms Carthy and Ms Mitchell for their compelling evidence and work. I also thank the enthusiastic research team who ably assisted the witnesses. If any of the organisations wishes to communicate with the select committee through correspondence on any of the key issues raised in our engagement, I ask that it do so.

Dr. Joanne McCarthy: I thank the Chairman and members.

The select committee went into private session at 5.30 p.m. and adjourned at 5.37 p.m. until 2 p.m. on Wednesday, 2 May 2018.