

DÁIL ÉIREANN

AN COISTE UM ACHAINÍOCHA ÓN BPOBAL

COMMITTEE ON PUBLIC PETITIONS

Dé Céadaoin, 16 Bealtaine 2018

Wednesday, 16 May 2018

Tháinig an Comhchoiste le chéile ag 1.30 p.m.

The Joint Committee met at 1.30 p.m.

Comhaltaí a bhí i láthair / Members present:

Teachtaí Dála / Deputies	Seanadóirí / Senators
Shane Cassells,	Jerry Buttimer,
Eugene Murphy.	Colette Kelleher.

I láthair / In attendance: Senator John Dolan.

Teachta / Deputy Sean Sherlock sa Chathaoir / in the Chair.

Business of Joint Committee

Chairman: Apologies have been received from Deputy Martin Haydon whom I wish well. His wife has given birth. I do not know whether it was a boy or a child, as we say down my way.

Senator Jerry Buttimer: A baby boy.

Chairman: We pass on our congratulations to the Deputy and his wife and family on their good news.

I ask members to, please, turn off their mobile phones. The usual provisos apply. Will they, please, switch them to airplane mode?

In accordance with the standard procedures agreed to by the Committee on Procedure for paperless committees, all documentation for the meeting has been circulated to members on the document database.

I propose that we go into private session to deal with some housekeeping matters. Is that agreed? Agreed.

The joint committee went into private session at 1.35 p.m. and resumed in public session at 1.50 p.m.

Senator Colette Kelleher took the Chair.

Decisions on Public Petitions Received

Vice Chairman: The first petition for consideration is No. P00017/18 from Mr. Mark Larkin who would like to see the voting age lowered to 17 years for the local and European elections in 2019. He believes that because many 17 year olds are in part-time employment, they are paying taxes and should have representation. It is proposed that the joint committee forward a copy of the response from the Department of Housing, Planning and Local Government to the petitioner and close the petition. Is that agreed? Agreed.

The next petition for consideration is No. P000015/18 from Mr. John Finnane. It concerns a complaint of abuse of an individual against An Garda Síochána. The petitioner states he has gone to the Garda Síochána Ombudsman Commission with the complaint - we have the reference number supplied - and received a response. It appears that he has also engaged with the Data Protection Commissioner. It is proposed that the petition be deemed to be inadmissible in accordance with Standing Order 111C(1)(h). Is that agreed? Agreed.

Personal Assistant Services for Individuals with a Disability: Discussion

Vice Chairman: At a previous meeting we considered the issue of personal assistant ser-

vices for individuals with a disability. To help us consider the matter further, I am pleased to welcome from the Department of Health Ms Patsy Carr; from the HSE Ms Marion Meany; from Áiseanna Tacaíochta Mr. Owen Collumb and Ms Eileen Daly; and from the Disability Federation of Ireland Dr. Joanne McCarthy and Mr. Garry Toner. I ask them to, please, turn off their mobile phones as they interfere with the sound system and the broadcasting of the meeting.

By virtue of section 17(2)(l) of the Defamation Act 2009, witnesses are protected by absolute privilege in respect of their evidence to the joint committee. If they are directed by the committee to cease giving evidence on a particular matter and continue to so do, 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. Opening statements and other documents submitted to the committee may be published on its website after the meeting.

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 Houses or an official, either by name or in such a way as to make him or her identifiable.

The presentations have been circulated to members. I remind the delegates that their opening statements should not exceed ten minutes in duration. They should pick out the key points because it is important that we have adequate time for dialogue.

Ms Patsy Carr: I thank the joint committee for its invitation to discuss personal assistant services for individuals with a disability. I am aware of its continuing interest in the issue and happy to provide whatever information I can and follow up with responses to questions in due course. I will provide an outline of the background to personal assistant services and the policy context in which they operate. I will also provide some detail on the nature and level of services being provided.

The term “personal assistance user” refers to a person with a disability choosing a personal assistant of their choice to aid him or her in everyday tasks and negotiating environmental, transport and other social barriers. However, all people with a disability do not want or require personal assistance but all people with a disability, including those who use or wish to use personal assistants, want to exercise choice, control and self-determination over their own lives. Government policy is to integrate services for people with disabilities with mainstream services, where possible. While the resources for the provision of assisted living services available are substantial, they are finite. The independent living philosophy underpinning the personal assistant service concurs with the approach that people with a disability should be empowered to live independently. The philosophy of independent living espouses living like everyone else, having the right to self-determination, to exert control over one’s life, to have opportunities to make decisions and take responsibility and to pursue activities of one’s own choosing, regardless of disability.

The role of a personal assistant is to assist a person with a disability to maximise his or her independence through supporting him or her to live in integrated settings and access community facilities. The personal assistant works on a one-to-one basis in the home and-or in the community with a person with a physical or sensory disability. A vital element of this personalised support is the full involvement of the individual service user in planning and agreeing the type of support and the times it is provided for him or her. Supporting independent living must

enhance the person's control over his or her own life.

Article 19 of the UN Convention on the Rights of Persons with Disabilities states people with disabilities should live where they wish and with whom they wish; that they should enjoy a range of community support services, including personal assistance; that they should enjoy community life and its opportunities on an equal basis to non-disabled people and that they should not be subject to isolation or segregation. The Department of Health and the HSE acknowledge the role of personal assistant services in supporting a person with a disability to realise the entitlements set out in Article 19.

Personal assistant services are accessed through an application process or referrals from public health nurses or other community-based staff. Individuals' needs are evaluated against the criteria for prioritisation for the particular services and decisions are then made on the allocation of resources. Resource allocation is determined by the needs of the individual, compliance with the prioritisation criteria and the level of resources available. While the resources available for the provision of personal assistant services are substantial, they are finite. Services are provided for those most in need in the context of the available resources and with consideration given to the other support services provided for the individual. In the normal course of service delivery there will be ongoing reviews throughout the year to ensure that, if needs change, the service provided will address this change within the available resources. An individual's personal assistant hours may be adjusted following a service review where service demand can result in one individual's service being reduced to address the priority needs of others with disabilities within the community.

Personal assistant services are, in the main, provided through a range of voluntary service providers. Some 80% of specialised disability services are delivered through non-statutory sector service providers.

In the 2016 census 643,131 people self-declared that they had a disability. Approximately 10% access specialist disability services consistent with their needs. Therefore, many do not require specialist disability services. The Department of Health and the HSE are committed to protecting the level of personal assistant, PA, services available to persons with disabilities. Year on year from 2013, the HSE has consistently increased the number of hours available to people with disabilities. In 2013, 1.29 million PA service hours were delivered to 2,057 people. In 2015, 1.48 million service hours were delivered to 2,369 people. In 2017, 1.51 million service hours were delivered to 2,470 people. This represents an additional 100,000 hours in excess of the targeted number for that year.

The level of service delivered is varied to ensure that each client's needs are reflected; therefore there is no average agreed number of PA hours per person. While many individuals are adequately provided for by their current level of support, it is recognised that many would benefit from more support hours. The number of PA service hours delivered in 2017, broken down by number of hours per week per individual is as follows: 1,097 people received one to five hours per week, while six to ten hours, 11 to 20 hours, 21 to 40 hours, 41 to 60 hours and 60 hours or more were delivered to 570 people, 419 people, 241 people, 67 people and 65 people, respectively. The need for increased services is acknowledged by the Department of Health and the HSE. The HSE continues to work with agencies to explore various ways of responding to identified need in line with the available budget.

Transforming Lives is the programme of reform under way to realise the overarching vision for disability services, namely, "to contribute to the realisation of a society where people with

disabilities are supported, as far as possible, to participate to their full potential in economic and social life, and have access to a range of quality personal social support and services to enhance their quality of life and well-being.” The national steering committee of Transforming Lives has agreed an outcomes framework following consultation with people with disabilities. This framework will help the HSE in identifying what outcomes are being achieved by individual services and what further actions are needed across the disability services as a whole.

The role of PA services, as outlined, is an important element in meeting the objectives of a number of key policy directions such as the approach outlined in the congregated settings report and the new directions report. As noted in the research, it is essential that there is co-ordination between Departments and Government agencies to provide a holistic approach across society to ensure full inclusion and self-determination for people with disabilities. However, all publicly funded services must adhere to employment legislation and appropriate health and safety training must be in place to protect both the service user and the employee. Garda clearance is also essential in ensuring the safeguarding of individuals. Given the move away from congregated settings towards a community-based and inclusive model of service provision, it is believed that the demand for PA and support services will increase significantly over time. The Department of Health and the HSE are committed to further developing the model in order that there is a consistency of approach and to ensure that the principle of self-direction is universally understood and applied. The HSE disability services team at a national level will lead a process to achieve this in consultation with service users and service providers.

I hope that this information is of assistance to the members of the committee. Myself and Ms Marion Meany, my colleague from the HSE, will be happy to answer any further questions.

Vice Chairman: I thank Ms Carr and invite Mr. Collumb to make his opening statement.

Mr. Owen Collumb: I am delighted to be invited here today to speak on personal assistant services to individuals with disabilities. Not so long ago, others would have been invited to speak on my behalf and to give their opinions on my life and the service I receive.

What is a personal assistant service and what does it mean to me? Personal assistant services allow people with disabilities to engage in everyday activities similarly to our non-disabled counterparts. The job of a personal assistant is not just to assist with our care needs like eating, dressing and household duties but also involves assisting with daily activities at work, school, or college and provides people with disabilities a full, meaningful position in the community.

On the international approach to personal assistant services, the right to live independently and to be included in the community is set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities, to which we have recently signed up. State bodies are obliged to put into effect measures to facilitate this right by ensuring that people with disabilities have access to a range of home services and other community supports, like personal assistant services, so as to be supported to live independently in the community.

On the distinction between PA services and other services, there are some key characteristics of a PA service that make it different from traditional care services to people with disabilities. First, the service user or the leader is the customer or employer. They choose who works for them and the working schedule of that individual. The service users customise the service around themselves. The funding follows the person and not the service provider. The person with the disability is not a passive recipient of the service but is engaged fully in the decision-making process. This is a key characteristic of any quality personal assistant service.

In recent times, we have seen a move towards direct payments as a support method for people with disabilities. Currently a draft report on the personal assistance package is before the Minister of State with responsibility for disability services. This will hopefully provide more choice and control for people with disabilities and their personal assistance packages. We in the Áiseanna Tacaíochta movement have also moved towards a personal assistant model. We commissioned NUI Galway to carry out a report on how our model is working. Some of its recommendations are highlighted in our presentation. The report shows the positive outcomes when people have choice and control over their own funding and their personal assistance packages. The key recommendations from this report are that every person with a disability in Ireland should be afforded the opportunity to direct his or her own personal assistant service and there should be a single assessment tool to evaluate each individual's right to a personal assistance package. As movement from one CHO area to another has been very difficult and bureaucratic, this should be improved and finally, personal assistance packages and funding should be extended to providing aids and appliances for ourselves to live more independently.

I will now hand over to my colleague, Ms Eileen Daly, who will explain further how personal assistance packages have made our lives much easier.

Ms Eileen Daly: I thank the committee for inviting me here today. I am going to speak about what I feel the future of the personal assistant service should look like and why I feel it is the best way forward. For me, the key difference that a personal assistant service makes to my quality of life and that of my peers is that it expands beyond everyday care tasks. While providing me with essential services such as personal care is absolutely essential because I cannot physically do it for myself, a PA service allows us to participate as equal citizens in society. To put it crudely, my personal assistant is an extension of me and my arms and legs. She empowers and enables me to carry out those tasks I cannot physically do. As a person with a disability, having control of my budget and the knowledge and understanding of from where money comes and how it can be spent and the fact that I am responsible for paying my staff is liberating and empowering, although it assumes a certain level of responsibility. Not everybody wants this or can deal with it, but for those of us who do, it is the way forward. It expands my quality of life beyond the home and enabled me to take up education and go to university before pursuing a number of postgraduate studies. Thankfully, it also allowed me to take up employment. I have many personal assistant hours, but without them, my full participation in society would not be possible. I work every day in the further and higher education sector. Therefore, I work to ensure people with disabilities and others are given equal access to education in their day-to-day lives. Part of it involves assisting them to progress to employment.

I refer to the different policies and legislative measures in place. The one that comes to mind is the comprehensive employment strategy. Many people need a personal assistant to access employment. Some do not, but a range of supports could be made available. Some are available such as assistive technology and so on, but when some people with disabilities leave education, they cannot take up employment because they do not have the supports they need. If they had access to a personal assistant service, it would allow them to take up part-time or full-time employment, if they wished. That would have a knock-on effect on the Exchequer and the economy, which would be a win-win. Personal assistants are employed and pay taxes; I am employed and pay tax, which removes me from the benefits trap. If this opportunity was afforded to others, many of them would take it to enter employment. However, it is also important to remember the needs of families. Direct payments allow families to have more autonomy and control over the way they manage their budgets for children and young people with disabilities. People's needs change throughout their lives. The needs of a child differ from those

of a teenager and evolve in adulthood. It is paramount to have a personal assistant service from the point of view of accountability and transparency and measures need to be built in to ensure this is upheld. Flexibility is required. Research to which Mr. Collumb alluded shows that when people with disabilities and their families are given ownership and control of their own budgets, it is more economical for everyone and has many benefits for society as a whole.

Mr. Garry Toner: I thank the joint committee for giving me the opportunity to contribute. I will deal briefly with the lived experience of having personal assistants. I have a team of four personal assistants working with me and they assist with everything daily. Previously I attended UCD to pursue a master's degree. I had a team of personal assistants while I was doing so.

It is important to note the difference between personal assistants and carers and home helps. Personal assistants assist people. They do not have to care for me, worry about me or look after my needs. I interviewed my personal assistants and then employed them. Three of them have been with me for ten years, while the other guy has been with me for five and a half years. It is important for me to engage in daily activities. For example, having completed the master's degree in UCD, I found a job as a disability officer in the Institute of Technology Tallaght. I have been working there for 12 years and on a regular day get up at 6.30 a.m. to go to work. I am one of those who gets up early to go to work. My personal assistant stays overnight and washes and dresses me and does everything everyone else takes for granted. I head to work at 8 a.m. I live on the Merrion Road and on average it takes an hour to get to Tallaght. The new personal assistant comes in at 8 a.m., drives me to work in my van and stays with me all day. As Ms Daly said, without my personal assistant, I would not be able to carry out my role as a disability officer in the Institute of Technology Tallaght. He assists all day in driving, preparing food, writing notes and so on, but I am still doing my job; he is there solely to assist. He drives me home in the evening when another personal assistant comes to prepare dinner. I then have some quality time for myself. For example, I go on the laptop just like everyone else, but I need a person to assist me, say, to get me a drink. If I need something, that personal assistant has to be there for me, as otherwise I would be unable to do anything because of my physical disability which is a form of spinal muscular atrophy.

I do not get up early at the weekend to go to work, but I engage in social activities. I go out to meet friends. My personal assistant drives me back and forth and, thankfully, I do not have to worry about public transport because I have my own van. I am glad that I do not have to rely on public transport. It all combines to give me a normal quality of life, just like everyone else. The personal assistants know exactly what they have to do. They know that they do not have to care for me and so on. They are told this at the beginning during the interview process and are worth it. That is why the personal assistant service is one of the most important issues. People hear about personal assistants and wonder what they do. They are not quite sure what a PA really is. People often assume that my PA is my carer, but that is not the case. I understand that people do not realise there is a difference. When people refer to my PA as my carer, I explain to them what my PA does. I explain that I have employed him myself on foot of an entire process.

Dr. Joanne McCarthy: I thank the committee for giving us all an opportunity to highlight the important role of PA services in supporting independent choices for people with disabilities. The Disability Federation of Ireland, DFI, is a national representative umbrella organisation with over 120 member organisations. It works to make Ireland a fairer place for people with disabilities. It is tough to follow the three preceding speakers because what I am going to talk about is really dry. I will build on some of the ideas introduced by our colleagues from the Department and the HSE. We are talking about the policy side, but the most important point

we need to make relates to the power of the lived experience. I stress that for many people with disabilities, PA services are critical if they are to be able to live independent lives of their own choosing in their own communities.

We have to appreciate that the term “personal assistant” is ill-defined and sometimes poorly understood by those inside and outside the disability sector. It is exhausting for users and advocates of the service to have to continually redefine and explain what constitutes a PA service. Recent DFI research has illuminated the fact that the general public cannot understand why an average person with a disability would need a PA service. People tend to conflate the concept of a PA service with the role of a CEO. They are very confused. We have to take that slippage on board and try to expose it.

We contend that there is a poor understanding of the definition and delivery of PA services within the disability sector. The kind of slippage to which I have referred is also found within the sector. The understanding of PA can differ from HSE or CHO area to HSE or CHO area. Obviously, some people understand clearly that by providing a PA to a person, or by supporting the provision of a PA to him or her, such a person can be enabled to participate in his or her local community, attend university, attend social events and be employed, etc. My colleagues have illuminated the benefits of PA services. We must acknowledge that the significant slippage which happens with PA services often takes place between the role of PAs, home supports and so on. We need to pay some consideration to the slippage between service types because it makes it difficult for us to qualify the true needs or requirements of a person from his or her PA service or home support service. When a person gets a limited home support service but it gets tagged as a PA service, the conflation of the two can confuse the outcomes and the outputs that are achieved through this process. This can often mean that people get a service which is not appropriate to their needs. A person who requires a PA may be provided with an in-house PA who is basically a home support, and then that gets conflated. We need to understand the impact this kind of slippage has on the real lives of people with disabilities who depend on PA services.

The DFI would strongly argue that a well-resourced, person-centred responsive PA service must be understood as the cornerstone of any community services programme that supports people with disabilities. It is important for us to remember that most people with disabilities do not live in congregated settings and do not depend on day services. They are people like my colleagues who are present - they are in their own homes or in supported accommodation in the community and are doing their best to participate as equals in their communities. The role of PA services is critical in that regard. They need PA services to enable and empower them to continue to live as others do.

We suggest that when the committee is beginning to consider how the concept of PA services should be defined, it should take the time to consider Article 19 of the UN Convention on the Rights of Persons with Disabilities, which defines the true value of what a PA service is. I suggest that the committee should use this as its guiding principle when it is considering what constitutes good PA services. While I do not want to labour the point, I must say that this is not an alien concept to us. It is well articulated in domestic policy. The role of PAs is covered in the national disability strategy implementation plan, the Transforming Lives programme and the value for money report. We have all bought into and accepted the key role played by PA services, but I think we need to look at the delivery of the service.

Vice Chairman: I ask Dr. McCarthy to conclude so that members will have enough time to ask their questions.

Dr. Joanne McCarthy: I will summarise what we are saying here today. It is important to emphasise that we are looking for an appropriate funding stream to enhance the capacity of PA services. Our colleagues in the Irish Wheelchair Association have estimated that the provision of 500,000 extra hours would enable almost 500 people to receive an additional 20 hours of assistance per week. This has been costed at €12.5 million, which is not a huge amount given that the total budget for disability services is €1.7 billion. The DFI is asking the committee to pay attention to the critical systems and systemic changes that are required to make the PA service a robust one. We are seeking a common or shared definition of “PA services” across the system - in health, education or employment - so that the role of such services can be better understood. We are calling for the introduction of a standardised assessment process that would create the right to access PA services across sectors like health, education and employment.

We are also asking the committee to pay attention to the huge anomalies in the data, which I have not had a chance to include in this presentation. Much of our information on unmet need is out of date and does not truly quantify the level of need that exists. I encourage the committee to consider how best to invest in data-gathering that enables us to truly plan for the delivery and enhancement of services.

The final point I would like to make is that greater investment will require greater oversight. There is a need to ensure, as part of the oversight process, that the independence which is a critical part of the governance of PA services, and enables people to live lives that include risk-taking as part of daily life, is not snuffed out. I have set out our key points.

Vice Chairman: All the presentations have been fantastic. I refer not only to the overview from the Department of Health, but also to the testimony of the lived experience of the benefits that accrue from access to a self-directed PA service, for example in respect of one’s employment and one’s social life. We have also heard about the bigger picture with regard to data gaps and the investment that is needed. I am sure the members have some questions.

Deputy Shane Cassells: I thank all the witnesses who have given us their time today. As Dr. McCarthy has said, there is a need to educate the members of this committee and the wider public about the services that are being availed of. I thank the representatives of the Department of Health and the Disability Federation of Ireland and, most importantly, those who have given their testimony and set out their lived experience. Dr. McCarthy has made a number of requests, for example for additional hours. Can she provide a breakdown of the statistics she has mentioned in this respect? Are the other witnesses seeking additional hours on an individual basis? Perhaps Mr. Toner, in his role as a disability officer in an institute of technology, can clarify what this would mean for people. What real meaning would come from additional funding? I am sure he would like a suite of measures to be implemented. If the request that has been made by Dr. McCarthy were actually implemented, what would that really mean? Maybe Dr. McCarthy can touch on that. She spoke about 500,000 additional hours and 500 people.

Dr. Joanne McCarthy: I think the number would be approximately 480. I will have to come back to the committee with definitive numbers. If €12.5 million were provided, just under 500 people with disabilities could receive 20 hours of assistance per week.

Deputy Shane Cassells: Okay.

Dr. Joanne McCarthy: That is still very little when it is spread out over the population. Of the 250,000 people in receipt of personal assistant services almost 1,000 receive between three and five hours service per week. This is not a proper service.

Deputy Shane Cassells: In regard to Dr. McCarthy's point that the data is out of date, is it significantly out of date and what level of investment is needed in data gathering to bring it up to a level which she believes is reflective of the challenges being faced?

Dr. Joanne McCarthy: There is consensus across the sector that the data is very much out of date and that it is not reflective of the reality of unmet need. I will have to come back to the Deputy on what is required in the context of keeping data live, particularly for those that are currently in the service delivery process, but it is a big issue.

Deputy Shane Cassells: Is it an accepted fact on the part of the Department and the Disability Federation of Ireland that the data is out of date?

Dr. Joanne McCarthy: In many cases.

Ms Marion Meany: The data is out of date but there is a huge onus on people with disabilities to actively help in that data collection. In 2000, we set up a physical and sensory disability database, one of the component parts of which is personal assistant services. When I reviewed the database to determine the number of people who had recorded a need for the service, or anticipated need over the following five years, there was very little data in this regard. We do not have the same ownership of the physical and sensory disability database as we do of the intellectual disability database. Our colleagues in the Department of Public Expenditure and Reform are of the view that we need this evidence. Every year we do include data to the best of our knowledge but Dr. McCarthy is correct that data is out of date. We cannot have information unless we are provided with it. If everyone with a disability who has a need for a personal assistant service registered that need on a database we would have a huge piece of information available to us immediately. There is nothing to stop people doing this. People need to take ownership and help us to do this piece of work. This does not require investment as the database is already in place.

Deputy Shane Cassells: Clearly, something is preventing people registering their need for the service.

Dr. Joanne McCarthy: The former health boards had a dedicated staff member whose job it was to keep databases live but there has been attrition in this regard over time and a lot of other things have happened. In addition, organisations, particularly the Irish Wheelchair Association, that are front-facing delivery services had to cease gathering data because doing so was creating an expectation that they could not answer. A colleague from the Centre for Independent Living told us that information on its database relating to the needs of people dates back five years and much of it has been archived. This means that people are waiting a very long time for services.

Deputy Shane Cassells: Is Dr. McCarthy saying that because there was an expectation that services would follow the collection of data, organisations and agencies stopped collecting the data?

Dr. Joanne McCarthy: It became almost untenable to continue to ask for that level of information when one had nothing to offer in response. Ms Meany is correct that enrolment on the physical and sensory disability database was voluntary. There were other issues caught up with that. Enrolment on the intellectual disability database was done at the point of service.

Vice Chairman: We must move on.

Senator John Dolan: I thank all of the witnesses for their opening statements. Does the

Department of Health consider less than 12 hours per week assistance to be adequate given what personal assistance is about? In other words, it is not in-home support but about liberating people and allowing them to live independent lives.

In regard to the table on page 5 of the Department of Health presentation, which sets out how the 2,500 is made up, does the Department consider one to five hours per week, six to ten hours per week and 11 to 20 hours per week adequate personal assistant service provision? If the HSE has knowledge of the level of need in personal assistance service provision, can it say yes. Is that within its gift? It was mentioned in the Department's opening statement that resources are finite.

Ms Patsy Carr: Yes.

Senator John Dolan: Perhaps the witness from the Department would respond to those questions before I move to the other witnesses.

Ms Patsy Carr: On the level of support, as I said, the level of support depends on the person's needs. For example, a person with a 40-hour need would be considered within the context of whatever services being provided to that person, as well as what other needs are required in the area for other people. As I said, resources are finite.

Senator John Dolan: There is a rationing of services by the Department in light of what is required for other people.

Ms Patsy Carr: Yes. On the adequacy of service provision and the number of people in receipt of zero to five hours, as I said, service provision is dependent on the person's needs. That level of service is sufficient for some people. I am not a clinician but much is dependent on a person's need. At the other end, a person may require 60 hours service provision and this must be considered as well. On the Senator's question of whether the Department thinks this level of service provision is adequate, the Department does not think anything is adequate. What we are doing is dividing up what we have and the HSE is providing based on need. The HSE is funded to provide 1.5 million hours and it has to work within that level of provision.

Senator John Dolan: That is fine.

Ms Patsy Carr: Under the legislation, the HSE is obliged to provide certain services, including residential services. The HSE is not obliged to provide a personal assistance service. This is an ancillary service that the HSE provides to meet people's needs within the context of everything else that is provided.

Senator John Dolan: I would like a response to the next question from Mr. Collumb, Ms Daly and Mr. Toner. In their estimation, what number of people have a need for a PA service or a significant increase in the number of hours service already provided to them, taking into account the definition of "personal assistant"? Mr. Collumb, Ms Daly and Mr. Toner are in employment. Perhaps each of them would comment on whether they would be able to work if they did not have a particular level of personal assistant service and also outline the band of service provided to them.

Mr. Owen Collumb: We know of many persons with disabilities who are not receiving adequate services. We know from the IWA research paper that between five and ten hours per week of personal assistant service has no meaningful effect on the lives of people with disabilities.

Senator John Dolan: In Mr. Collumb's opinion, is less than ten hours per week not a PA service?

Mr. Owen Collumb: It is not a personal assistant service and, also, it is not having any meaningful effect on those people's lives.

Mr. Owen Collumb: It is not a personal assistant service. Also, it does not have any meaningful effect on those people's lives, as reported by the IWA. It is such a small system. A person may drop in and assist a family member with the task of getting out of bed. That assistance is essential but that level of service does not have any meaningful effect on that person's life.

The Senator asked about the service I have. I get more than 100 hours per week. My life begins when my personal assistant arrives at the front door and it stops when my assistant goes out the front door. My history is one of institutionalisation. I was put into an institution following an accident. I had a motorbike accident and, following it, I was institutionalised when I was 21 years of age. I had no choices over the control of the services I received in there. Now I live independently in the community. I work and I pay taxes. I get up in the morning and go out. There is no way that would happen without my having a quality personal assistant service.

Vice Chairman: The level, extent and quality of the personal assistant service are critical.

Mr. Owen Collumb: It must be a quality personal assistant service, otherwise I would not leave my home. I need to be back home at a certain stage. There are many hours during the day when I do not have a personal assistant service. That is almost downtime. I do what I can on the computer during that time while I wait for the other personal assistant to come in to get me something as simple as a drink of water. That is how essential this service is. The service cannot be spread too finitely throughout the whole disability sector, otherwise it would not be a personal assistant service and people would only get the crumbs of a service. It would not be a service.

Vice Chairman: Would Ms Daly like to answer some of the questions that were raised?

Ms Eileen Daly: Absolutely. I know many people through my work and friends who would benefit hugely from having a personal assistant service and who have gone to college, be it further or higher education, and excelled. I am not being dramatic when I say they literally experience depression and sometimes other mental health issues because they are left at home. They have kept busy and active all their lives. They have engaged, participated, had friends and perhaps boyfriends or girlfriends and then are simply left alone either in the family home or some are institutionalised. There are many people who would benefit from having a personal assistant service. I cannot give a precise number but there are many.

Focusing on myself, as Mr. Collumb said, I could not function without a personal assistant. I would not have any quality of life without that support. I would not have been able to go to college. I certainly would not be able to have a job. I would literally be stuck at home doing nothing. I might have some degree of a social life but it would be very restricted and, sadly, I would not have any quality of life. It is important to point out that when people feel that they have voice and are important and can contribute, it reduces the pressure on all the services, ranging from acute hospital services to the closed spaces or the congregated settings to mental health and psychiatric services. It has a knock-on, ripple effect on everything. A quality personal assistant service is needed. It is not all about me, doing what I do. Getting a right day service allows me to go out spread the message and assist others. For me, that is hugely

important here as well.

Vice Chairman: Thank you, Eileen. I call Mr. Toner.

Senator John Dolan: Into what bracket of service hours shown in the table in the presentation would Ms Daly fall?

Ms Eileen Daly: In terms of the number of hours?

Senator John Dolan: Yes, roughly.

Ms Eileen Daly: I have more than 100 hours a week.

Senator John Dolan: Okay.

Vice Chairman: I would now like to hear from Mr. Toner.

Mr. Garry Toner: I welcome everything the two previous speakers said. I know some people would could do with having more personal assistant hours. There may be a gap in the day when they are sitting at home with no one and are waiting for someone to come in. My situation is slightly different because I have students coming into me. Students see me working as a disability officer and see that I have personal assistants. I provide personal assistants for students in the same way they are provided for students in every other college. Students have academic personal assistants while they are in college but, unfortunately, when those academic personal assistants are gone, the students are left on their own. One particular student who is a wheelchair user recently came to me and asked how he could become independent and live independently like I do. I told him the process but, unfortunately, my fear is that he will not get enough hours to allow him to live independently. If he gets one to five hours per week, there is no way he could do that. That student, who has quite a severe physical disability, is doing great at college. I told him what the process involved even though it is not my duty to do so but I am fearful he would only get the crumbs of service hours. What use would that be to him?

Vice Chairman: I am anxious to bring in the other members. Does Senator Buttimer have a question?

Senator Jerry Buttimer: Yes. I thank Mr. Collumb, Ms Daly and Mr. Toner for their presentation, Ms Meany and Ms Carr and also the personal assistants for being with us, for participating and for allowing us to have this engagement. To be fair, Senator Dolan asked a rhetorical question about the personal assistant service. Mr. Toner spoke about the lived experience. We are seeing here the embodiment of the lived experience and the need for a model of delivery of a personal assistant service that is people-centred. If I may, I would disagree with Ms Daly and say that it is about her. She must be at the heart of what we do in the context of the personal assistant service. She is a tremendous advocate and I do not say that in a patronising way. It is because of our interaction today that we can shape policy for the future and also help to move funding.

Dr. McCarthy and Mr. Toner mentioned data in their paper as did Ms Carr and Ms Meany. Data needed to be collected, whether it would be done voluntarily or otherwise. As a former chairperson of the Joint Committee on Health and having been involved in an organisation such as that with which the Vice Chairman is involved in the past, I am aware that the collation and collection of data helps to change the system for the betterment of the person who must be at the heart of what we do. That is important.

We tend to throw out different phrases and words. How would the direct payment model give the witnesses more autonomy and control? If I am out of order in asking the next question, the Vice Chairman can rule me out of order. The personal assistants might comment on the way they think the service could be changed?

Vice Chairman: If we have time, we will ask them.

Senator Jerry Buttimer: It is important we would hear from all sides.

Vice Chairman: The Senator's question was on the direct payments

Senator Jerry Buttimer: That was my first question. I have gone on a little and I apologise for that. Whose job is it to govern the quality and the delivery of the service? I note in her paper on the quality issues, Dr. McCarthy of the Disability Federation of Ireland said that it was not the job of the HSE to do that. She also said that the Health Information and Quality Authority, HIQA, has a paper exploring the regulation of health and social care services. Whose job is it to oversee, monitor and regulate the quality?

In the context of the Department of Health, with the move away from congregated settings, we all want to see community-based settings and people living independently. Senator Dolan used the word rationing, with which I do not agree. If there is an inadequacy in the service and if no meaningful value is being given to the person, how can we change that for the betterment of person, notwithstanding and accepting that we do not have a rainbow with a crock of gold at the end of it?

Vice Chairman: The Senator's question is about the direct payments, the governance, equality and-----

Senator Jerry Buttimer: Yes. To be fair, the three people who have presented this afternoon have shown in a lived way the importance of the personal assistant, PA, service model of delivery, whether it is the number of hours or whatever. How can we make that service better and deliver it in a way that ensures that the needs of the person are met? I refer to a person who requires, say, ten hours. I agree the service is clinician led and I accept that I would not be able to make a determination but if someone needs an increase in the number of hours, why can we not give that person the extra hours in association with the clinician or whoever?

Vice Chairman: Would the Department like to answer that question?

Ms Patsy Carr: The Senator also asked about moving from a congregated setting. Currently, the PA hours are available for those with sensory and physical disability but as we move from congregated settings, perhaps people with an intellectual disability, ID, will need some services as well. Currently, we do not have an agreed definition of the ideal service. Obviously, we will develop a policy around that in conjunction and consultation with our service users.

Senator Jerry Buttimer: I am sorry, Vice Chairman, but we have a vote in the Seanad.

Ms Patsy Carr: It would be our intention to do that but we need to be sure that any service we develop is mindful of the outcomes framework so that the quality of people's lives continue to improve. The service to be delivered also has to meet specific requirements, and it must stand up to scrutiny. There is employment law to which people have to adhere. There have to be health and safety requirements and everybody has to be Garda vetted. Government structures have to be in place for any service we are developing.

Vice Chairman: Ms Carr said that the policy was in development.

Ms Patsy Carr: We are committed to developing a policy but we have not started it yet.

Vice Chairman: Does Deputy Murphy have any questions?

Deputy Eugene Murphy: I first want to apologise to the witnesses. It has been a very busy day. I had to go out to another engagement so I am sorry I was not here when they arrived. Along with other members, I want to offer a céad míle fáilte to all the witnesses, including those who are here taking care of them including Ms Daly, Mr. Toner and others.

In terms of what I have heard since I arrived, I fully support that for which the witnesses are advocating. I have one or two questions. I read in the document provided that the Disability Federation of Ireland states that 120 member organisations provide support and services to people with disabilities. That is a huge number of organisations. In terms of their make-up, I presume they are located locally and regionally throughout the country. Do not get me wrong but could that be streamlined to work better in the witnesses' favour? I do not mean from the point of saving money or anything like that but do they believe that if the Department looked at that and if it was co-ordinated differently, it would be of benefit to them?

Vice Chairman: That is a question about the membership organisation more than the personal assistants, which is what we are focusing on today. It is a good question but perhaps it is for another day.

Deputy Eugene Murphy: I presume there are many personal assistants involved in many of those organisations.

Vice Chairman: Not all of them, I would say.

Deputy Eugene Murphy: It is only for my own information.

Senator John Dolan: There are not 100 organisations out of that providing PA services. There are one or two big players and then there is a number of-----

Dr. Joanne McCarthy: There are two models in that regard. For example, Áiseanna Ta-
caíochta, AT, is here today and it is a player in the delivery of a personalised service.

In terms of the numbers of organisations, they are not all equal. There is a general misunderstanding of the term "disability organisations". This is probably going beyond the agenda but not all those organisations are equal. Some of them are very large players such as St. Michael's House, the Irish Wheelchair Association, IWA, and the other household names we all know. Others are very local family or individually led organisations that are facilitating local community participation. The figure of 100 can be misleading but the investment behind that at all levels is what we need to walk away with, so to speak. There are not 100 large organisations vying to deliver services. They are all delivering and responding to very particular needs.

On the question of whether there is capacity to bring about synergies, without a doubt I am sure there are issues in that regard. Some organisations work very well together at local level to create that synergy so that the person who is experiencing services from three or four different organisations is getting them in a seamless way. There are probably improvements that can be brought to that and that is something we work with through people's service arrangements with the Health Service Executive, HSE, at community healthcare organisation, CHO, level. That is an ongoing commitment and those of us within the sector are always trying to find better ways

of bringing about those synergies.

Deputy Eugene Murphy: I thank Dr. McCarthy. I wanted that just for my own information. It is not that I am trying to suggest anything on which to cut back. I know there will have to be many organisations up and down the country. In my locality in the west and the midlands, there are many different groups helping out with which I have been involved for years. I presume all of those come under these 100 plus organisations.

Dr. Joanne McCarthy: An important point that is always missed is that not all these organisations are fully funded or receive any funding.

Deputy Eugene Murphy: That is true.

Dr. Joanne McCarthy: Many of them are bringing in additional resources, knowledge and voluntary contributions and therefore they are a vital element to that infrastructure of support that is available. The critical added value these organisations can bring in can get lost in the very simple debate around too many organisations.

Vice Chairman: Ms Meany indicated that she would like to contribute. I will then draw the discussion to a close.

Ms Marion Meany: There are certainly small organisations that are not funded but the Deputy is right that quite a number are significantly funded. We have 50 organisations that get between €3 million and €170 million. We have a further 50 that get between €1 million and €3 million and another 30 that are below that. Within the disability arena alone we have a very significant number so energy has to be put into considering how we protect and reinvest in the front-line services rather than building structures in organisations. It is a valid point that it is a piece of work we have to examine.

Vice Chairman: I will adjourn shortly because we are conscious of the time. We decided to look at this as a committee because we had a presentation from Leigh Gath, who was presenting on her role but who also spoke about her own personal experience and therefore we got interested in the personal assistants. This has been a very educative process for me today as it was about the impact of a PA service on a person's life in terms of accessing employment, a social life and so on. I thank Owen, Eileen and Jerry for painting that picture very clearly. I thank the Department witnesses also for giving us the facts and figures on the number of people and hours. We had an interesting debate about the definition. Can it be called a personal assistant service with ten hours being provided? We also spoke about the juggling, the rationing and the need for a policy on all of that.

One of the things committees like ours can do is draft reports. Given that this is a policy development area, it might be helpful for us to do so that we could draw together the experiences.

Senator Buttimer spoke about hearing from the PAs. It would not be fair of us to put them on the spot today but we could take a submission from them to complete our knowledge. We might take submissions from elsewhere as well.

I propose that the committee would issue a report on the personal assistant service. Their policy is in development so it might be a useful contribution to their thinking and capturing the benefits but also some of the current critical issues.

The meeting has been very useful. I thank the people in the Gallery who attended also.

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The joint committee adjourned at 3 p.m. until 1.30 p.m. on Wednesday, 30 May 2018.