

DÁIL ÉIREANN

AN COMHCHOISTE UM SHLÁINTE AGUS LEANAÍ

JOINT COMMITTEE ON HEALTH AND CHILDREN

Déardaoin, 19 Samhain 2015

Thursday, 19 November 2015

The Joint Committee met at 9.30 a.m.

MEMBERS PRESENT:

Deputy Catherine Byrne,	Senator Colm Burke,
Deputy Joe Costello,	Senator Thomas Byrne,
Deputy Seamus Healy,	Senator John Crown.
Deputy Billy Kelleher,	
Deputy Sandra McLellan,	
Deputy Mary Mitchell O'Connor,	
Deputy Dan Neville,	
Deputy Caoimhghín Ó Caoláin,	

In attendance: Senator David Cullinane.

DEPUTY CIARA CONWAY IN THE CHAIR.

The joint committee met in private session until 10.15 a.m.

Disability Issues Update: Minister of State at the Department of Health

Vice Chairman: I ask members and delegates to ensure their mobile phones are switched off as otherwise they cause serious problems for broadcasting, editorial and sound-recording staff.

I welcome the Minister of State, Deputy Kathleen Lynch, and her officials, Ms Frances Spillane, Mr. Kieran Smyth and Ms Grainne Duffy. I also welcome Mr. Pat Healy, national director for social care at the Health Service Executive.

The main focus of the meeting is on providing the joint committee with an update on disability issues. It is important that we have an opportunity to engage with the Minister of State specifically on the theme of disability. In recent months the committee has done a lot of work on a range of issues in this area, including on proposals for a national vision strategy to incorporate deafblindness and community funding for people with intellectual disabilities. We are interested in receiving an update on the move away from congregated settings to more person-centred care. In our second session later today we will be meeting an umbrella group which represents different organisations that work with assistance dogs.

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

I invite the Minister of State to make her opening statement, after which I will take questions from members.

Minister of State at the Department of Health (Deputy Kathleen Lynch): I thank the joint committee for the invitation to attend to discuss disability issues. I appreciate its interest in this important matter. As the Vice Chairman indicated, I am joined by Ms Frances Spillane, Mr. Kieran Smyth and Ms Grainne Duffy from the Department of Health, with Mr. Pat Healy, national director of social care at the HSE.

The Government, statutory and non-statutory agencies which provide services for people with disabilities have been working towards the goal of enabling disabled citizens to live as independently as possible, with appropriate social, housing, employment and all other mainstream supports from the State. Our aim is to transform services to provide a model of personally chosen supports designed to enable the individual to live a normal life in society.

During 2015 funding of almost €1.5 billion is being provided for health and personal social services. It is important to illustrate the range and complexity of the services and supports this significant figure encompasses. Residential services are being provided for some 9,000 people

with disabilities at more than 1,200 locations. These facilities range from large congregated settings to community group homes to supported independent living. Day services are being provided for approximately 22,000 people at 850 locations. Some 1,400 young people who left school and rehabilitative training programmes this year have received new services and supports. Respite residential support, amounting to 190,000 overnight stays, is being provided. The target for the provision of personal assistance or home supports in 2015 is 3.9 million hours. A variety of other services are also provided under the disability services programme, including non-centre-based respite care, early childhood and family support, community-based medical, nursing and therapy services, rehabilitative training, and aids and appliances.

I will outline briefly how disability services are supporting people with disabilities from childhood onwards and the major reforms taking place in children's disability services. Implementation of the HSE's national programme for progressing disability services for children and young people, covering birth to 18 years of age, involves a reorganisation of existing therapy services into geographically based, multidisciplinary, early intervention and school-aged teams. The key objective of the programme is to bring about equity of access to disability services and consistency in service delivery. There should be a clear pathway for children with disabilities and their families to services, regardless of where they live, what school they go to or the nature of the individual child's difficulties. Some €8 million in additional funding has been invested in 2014 and 2015 to fund 200 additional posts to support the implementation of the new model.

Improving access to children's therapy services is a particular priority for the Government, not only in disability services but also in primary care. An additional €20 million was allocated in 2013 to strengthen primary care services and to support the recruitment of prioritised front-line posts, including more than 260 additional posts for primary care teams. Further funding is being provided in 2016 to expand the provision of speech and language therapy in primary care and to support the reorganisation and expansion of speech and language and other therapies under the progressing disability services programme. Full implementation of the progressing disability services programme is expected before the end of 2016.

This brings me to the matter of health-funded supports for young people after they leave school. Government policy is to enable young people with disabilities to develop the skills they will need to live independent lives to the greatest extent possible and to receive the supports they need in order to achieve this. Every year, young people finish their second level education and progress to the next stage in their lives. For most, the hope is that they will progress directly to further education, vocational training or employment. However, young people who have more complex support needs will initially rely on life-skills training or day supports provided by the HSE. Additional funding of €12 million was allocated by the HSE to meet the needs of around 1,400 young people who require continuing health-funded supports on leaving school or rehabilitative training this year. Some €6 million of this has been made available to provide services from September. The provision of services to these numbers of young people has, in recent years, posed a challenge to the HSE. When this year's support requirements were identified, the cost of meeting those needs in full exceeded the amount available. I am pleased to say that an additional €1.5 million was added by the HSE to the overall allocation, making a total of €13.5 million full-year costs available to meet those needs. A further €1.5 million once-off capital funding was also allocated by the HSE for the provision of suitable buildings, premises and accommodation. There is an onus on us all to use the substantial resources committed to disability services throughout the public sector more effectively and efficiently and, most importantly, we must ensure that we are achieving real and significant improvements in the lives of people with disabilities.

Transforming Lives is the programme to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland. This transformation of our disability services will mean that person-centred and individually chosen community-based supports will increasingly become the norm, which is a distinct move away from the group-based, often segregated approach of the past. People with disabilities will be supported to make the types of choices about their lives which are available to everyone else in society. This new approach will be underpinned by a more efficient method of assessing need, allocating resources and monitoring resource use.

We can see this person-centred approach being progressed by the HSE in the provision of day services, as outlined in the New Directions report on HSE-funded adult day services. Service providers are actively engaging in delivering services which have a person-centred focus, with person-centred planning now widely implemented, along with an increase in the delivery of community-based day services. Service providers are taking practical steps to support and actively engage with people with disabilities in community settings and are exploring new and innovative ways of doing this, including through a range of demonstration projects. An example of this is the Next Steps Project, a network of shared learning and support, set up by the National Federation of Voluntary Bodies, involving people with disabilities, their families and their key workers. A measure of its success is the fact that the project received an International Zero Project Innovative Practices award earlier this year at the United Nations headquarters in Vienna.

Person-centred planning also underpins the movement of people with disabilities from congregated settings into the community. In July 2012, the national implementation framework was launched to support the Government's National Housing Strategy for People with a Disability 2011–2016. This continues the successful collaborative approach between the Department of Health and the Department of the Environment, Community and Local Government. The implementation framework reflects the recommendations of the mental health policy, A Vision for Change, and in respect of disability, Time to Move on from Congregated Settings - A Strategy for Community Inclusion.

The congregated settings report identified that in 2008, around 4,000 people with disabilities were living in congregated settings, which the report defined as residential settings where ten or more people with disabilities live together. I am aware that implementation of the report will introduce a huge change for people, including people with disabilities, their families, service providers, the HSE, various Departments, statutory bodies and representative organisations. To ensure that the needs of people transitioning from congregated settings are fully taken into account during the process, the model of care will be based on a person-centred plan.

The HSE has established a working group under the Transforming Lives steering group, which is developing an implementation plan for the process which will be rolled out at regional and local levels, in full consultation with the stakeholders. At the end of August 2015, there were around 2,800 people with a disability living in congregated settings. In 2015, the HSE prioritised the transition of people from congregated settings under its social care operational plan and the target was for 150 people to move. So far this year, 84 people have moved and the HSE will accelerate implementation of this policy next year.

The Government is very committed to the protection and safety of our most vulnerable citizens. We placed regulation and inspection of residential and respite care disability centres on a statutory footing in November 2013. The purpose of the regulations is to safeguard and support the delivery of person-centred care to vulnerable people of any age who are receiving residen-

tial care services and to ensure that their health, well-being and quality of life is promoted and protected.

Compliance with national standards for disability residential centres is now a requirement under the service level arrangements between the HSE and voluntary service providers. More than 1,000 inspections have taken place to date and the lessons learned from those inspections are continuing to improve the quality of services. People with disabilities and their families can be assured that this regulatory regime is being rolled out across all residential facilities.

I am aware that while the Health Information Quality Authority, HIQA, has reported evidence of good practice in the delivery of many residential services, where the support and care needs of residents have been prioritised, it is also sadly true that some of HIQA's findings can make for difficult reading. However, those findings serve as evidence that the regulatory process works effectively and in the interests of protecting vulnerable people in the care of the State. They serve to increase our determination to ensure that the regulatory regime is used to shine a light on poor, out of date practice and make real and tangible changes in people's lives.

The HSE is implementing a comprehensive change programme of measures to improve the quality of residential services for people with disabilities. The HSE has also appointed an independent person as a confidential recipient. This role supports the implementation of the policy launched in December 2014, Safeguarding Vulnerable Persons at Risk of Abuse.

I asked the National Disability Authority, NDA, to undertake an independent review of the impact of one year's implementation of the registration and inspection system, focusing on the actual experience of those who have been involved in the inspection process. This has included service users and their families, the HSE, HIQA, service providers and organisations representing people with a disability. The NDA's report is being finalised at present. It will be supported by an advice paper which will guide us in determining next steps in implementing the learning from their analysis.

Plans for 2016 will be set out in detail in the HSE's service and operational plans. While we intend to move on implementation of our policy objectives, 2016 will involve consolidation of the existing significant resources invested in disability services. The actions for next year will include a major focus on ensuring we are getting the best value for that investment. This will include use of a service reform fund, recently established by way of agreement between Atlantic Philanthropies, the Department of Health, the HSE and the Genio Trust.

I welcome this opportunity to discuss the Government's position on services for people with disabilities. Central to that position is the recognition that people with disabilities have the same goals, aspirations and abilities as every other citizen and the same right to participate in society and to make a contribution. While we are making good progress in achieving a fully inclusive and equal society with appropriate services and supports for people with disabilities, we still have work to do. I assure the committee that I am firmly committed to that task.

Deputy Caoimhghín Ó Caoláin: I welcome the Minister of State, Deputy Kathleen Lynch, and her colleagues. In the area of disabilities, in particular, children with disabilities, there are so many issues we could address. I would like to highlight a number of them, some of which the Minister of State referenced in her opening remarks, including the 190,000 overnight stays in respite residential support centres.

In the course of her presentation, the Minister of State made reference to what was being

provided, understandably so, but I am sure she will agree that much more must be done not only for the person with a disability but also for his or her immediate carer, loved one and so on. Respite care is hugely important. It is not that the extent of the need is unfathomable, but the number of overnight stays needs to be significantly increased to make a critical difference not only for the person with a disability but also for his or her carer. Without carers, many people with disabilities could not continue to live at home or in community settings. It is important in my opening remarks on people with disabilities that I make reference to those who provide such stoic, heroic support for them on a daily basis, year in and year out.

On the targets for the provision of personal assistants and home supports, again, there is, undoubtedly, a need for a significant increase in the hours provided across the country. Personal assistants and home supports are crucial. It is right that I reference this issue in following on the earlier reference to carers and the need for respite care. Some 3.9 million personal assistant and home supports hours were provided in 2015. I accept that the service plan has not yet been published for 2016, but is the Minister of State in a position to tell the committee what improvements, as a result of promised measures, we can expect to see in 2016 on the performance in 2015? I note that Mr. Healy who has responsibility for the social care area is accompanying the Minister of State. Perhaps he might like to comment on that issue also.

There are a number of congregated settings around the country in which there has been little, if any, capital investment for many years. I am speaking not only about facilities for persons with physical disabilities but also for people with intellectual disabilities. I recently visited a facility I had occasion to visit on a more frequent basis many years ago and was concerned to note that it had not been upgraded or updated in any way since I had last visited it. I am also concerned about the registered nurse intellectual disabilities, RNID, cohort employed not only in congregated settings but also across the community sector. RNIDs perform important work, but there is real concern that the training, professional knowledge and experience they bring to their respective positions are somehow being diminished by the idea that they are replaceable by care assistants who do not have the training or experience or potential to make a critical difference to an individual. I would, therefore, welcome a comment from the Minister of State on RNIDs. It is essential that their full range of skills be employed as an integral part of the care supports provided for people with intellectual disabilities, many of whom are in care settings.

At this stage I would like to make reference to an individual case that I believe is reflective of a serious problem across the country. I speak about the group home which has been promised for ten years in my constituency, in the main for young women with physical and sensory disabilities. Ten years on construction of this essential facility in Carrickmacross, County Monaghan has not commenced. There is concern across the political spectrum about this matter. I recently tabled a parliamentary question about it, in respect of which I have spoken to staff in the Department of Health in preparation for its response. The Department, the HSE, the Department of the Environment, Community and Local Government, Monaghan County Council and the housing association Respond have acted as five silos during the years in this matter, with one demanding a response from another on this, that and the other. The absence of joined-up thinking resulted in the mother of a daughter with special needs who has since passed on never having certainty in her later years that her daughter would be properly catered for post her time on Earth. Another young woman, whose parents are now in their 70s, is awaiting construction of this facility, yet in the past ten years not one brick has been placed on another. This project has been approved in principle. All of the entities to which I have referred are willing to give it their full support, but no one seems to be willing to take the lead to ensure commencement of construction of this facility is given the green light. I am sorry to use the

opportunity of today's meeting to refer to a specific matter, but it is an example of the problems we encounter with governance in general. I am not referring to particular Government parties but to governance in the permanent government and the need to have joined-up thinking and action in the interest of special citizens, and all citizens.

Deputy Seamus Healy: I welcome the Minister and the officials from the Department and the HSE and I thank the Minister for her presentation. The final paragraph of that presentation is key to the disability area. Part of it is worth quoting: "[P]eople with disabilities have the same goals, aspirations and abilities as every other citizen, and the same right to participate in society, and to make a contribution". That is what we all wish to see happen in a reasonably short period of time.

We have been contacted by the Disability Federation of Ireland and we are very concerned about this area. The 600,000 people with disabilities do not consider that they were protected during the recession or that they were the priority social justice issue, as was promised by the current Taoiseach in the last week of the 2011 general election campaign. There is also serious concern in the disability community that not only was it not protected during the recession, but that it will be sidelined to some extent in the current situation where the economy appears to be recovering. That view is held by a significant number of people with disabilities and I hope the Minister and the Government take it on board. We have received correspondence about this from the Disability Federation of Ireland.

A series of issues is dealt with in the presentation. I wish to highlight and seek further information on three of them. On the issue of the transfer of persons with disability from congregated settings, I note that the HSE target for 2015 was to move approximately 150 but only 84 have taken place. Currently, there are 2,800 people in those settings. Perhaps the HSE representative could tell us what the plan is for moving people from these settings. What period of time is involved? If it continues to operate on the basis of 150 per year, it would be a considerable length of time before it would be addressed and finalised.

Regarding acquired brain injury, a significant number of people, approximately 10,000, acquire a brain injury every year. What services are available for people with acquired brain injury?

Finally, there is the issue of work. The entitlement of persons with disabilities to work and avail of training is a key concern of the disability community. It appears, and I am subject to correction on this, that the programmes under the Youth Guarantee scheme are not open to persons with disabilities or, indeed, those on illness payments. Similarly, the Momentum programme does not appear to be open to people with disabilities. Can the witnesses comment on that?

Deputy Sandra McLellan: I welcome the Minister of State and her officials, and thank her for her presentation. It covers a vast range of services across the sector so I will concentrate on a few points.

The Minister of State mentioned enabling our disabled citizens to live as independently as possible with appropriate social housing. We have raised this matter on a couple of occasions in the committee. Many people with disabilities who are living in social housing have difficulty accessing grants to adapt their housing. There is concern that some people are waiting on lists for years and cannot get their houses adapted through the local authorities. There is some type of breakdown between the Department of Health and the Department of the Environment,

Community and Local Government or local authority housing departments on this. Is the Minister of State or her Department doing anything to try to improve that situation?

Regarding some of the figures the Minister of State gave in her report, have they improved since 2011 and by how much? The 190,000 overnight stays are being provided to people with both physical and mental disabilities. There are approximately 600,000 people in the country living with disabilities but those figures only provide two weeks of respite for approximately 13,500 people. When one breaks it down like that, it does not appear to be much. In addition, there does not appear to be a huge facility for people who are caring for people with mental health issues to access respite care. I have been dealing with carers of people suffering from mental health issues and they found it very difficult to access respite services. How is the 190,000 figure broken down with regard to mental health and disabilities?

Another issue is children with mental health problems accessing services. It has been brought to my attention that counselling services are very limited. It depends on where one lives in the country and how one accesses them. It has also been brought to my attention that they are not very consistent. It is hard to get consistency even if one manages to get counselling appointments. When one returns one often meets a different person, so the young person is constantly repeating themselves. How is the Minister addressing the gaps in that service regionally?

With regard to the €1.5 million once-off capital funding, what is that allocated for? As regards accessing services, the Minister of State said there should be a clear pathway to services for children with disabilities and their families, regardless of where they live. It has been brought to our attention that when people with disabilities who live in a rural area leave mainstream school at 18 years of age and require follow-on services, they often cannot get transport to and from these facilities. What is the Minister's opinion on that?

Deputy Dan Neville: I, too, thank the Minister of State for her presentation. My colleagues have raised some of the issues I wished to raise so I will not dwell on them at length. Prior to the economic crash there was much concentration on the employment of people with disability. My recent checks on this area show that the public service is still at its target. Given that the target was set approximately 15 years ago, has consideration been given to increasing it for the public service? There was a strong media campaign and a discussion within the body politic regarding private and non-State companies employing people with disabilities. We were all very interested in the area of employment and disability until the crash when the entire employment situation changed. Now that, according to yesterday's figures, we are moving back towards 2008 levels, let us engage again with the employment of people with disabilities. I have spoken to individuals who have taken on those with disabilities I have never heard any of them say that the disability interfered with a particular person's performance. In fact, the opposite was the case. The employers with whom I spoke found that people with disabilities were extremely conscientious workers and contributed greatly to the business. There is an opportunity to promote that area and to look at the public service in the context of employing such people.

Previous speakers referred to disability. I raise the matter of acquired disability, which we appear not to include in our discussions. There is a big change in a family when one of its members suffers a stroke, for example. Sometimes stroke is not seen as being on the disability spectrum but, of course, it is on that spectrum. Concerns arise in respect of the adaptation of houses, change in lifestyle and so on. If one has a medical card, one will be eligible for certain services. There is a whole range of issues we do not include when discussing disability. We see something as a disability but we do not include those with such a disability in the overall

discussion relating to disability services.

Aging can also give rise to disability. The issue with which we, as public representatives, are all confronted is that of grants for the adaptation of houses by means of the installation of shower facilities, handrails, lifts and so on. Sometimes there is an immediacy about these things because people may become disabled at a certain age. We all know of families who try to bath an elderly person and who may have to wait six or 12 months to convert to a shower.

Deputy Caoimhghín Ó Caoláin: I apologise for interrupting but Second Stage of the Health Insurance (Amendment) Bill 2015 is commencing in the Dáil.

Deputy Kathleen Lynch: I understand that.

Deputy Caoimhghín Ó Caoláin: I am sorry that I cannot remain to hear the Minister of State's responses. I thank for them in advance. My colleague will note and advise me of them afterwards.

Vice Chairman: Shall we take Deputy Catherine Byrne now and then the Minister of State can respond?

Deputy Catherine Byrne: I am sorry I was not present but I was listening to what the Minister of State on the monitor in my office. I support Deputy Dan Neville in respect of adaptation grants for showers and so on. If, for whatever reason, one wants one's bathroom renovated, it is great if one has a person with a disability - old or young - in the house and if one owns that house. If, however, one is a tenant of Dublin City Council or South Dublin County Council, then it is impossible. I give full marks to Dublin City Council and South Dublin County Council because when they are contacted regarding a private resident who wants a walk-in shower, a new bathroom or a new toilet installed, the job is done and the grant is paid within a couple of weeks. If one is a Dublin City Council tenant, if one lives on the second floor of, for example, Oliver Bond Flats and if one has a disability, one will find it almost impossible to get Dublin City Council to carry out adaptation works to one's dwelling. One cannot be given a flat downstairs because it will not be suitable. There are people waiting for extensions.

I have a constituent who is severely handicapped and in a wheelchair. His mother struggles to take him up and down the stairs, to bath or shower him, etc. She has an old seat in which she puts him when she is bathing him. I have been trying to get an extension built on to their house for the past five years. Every time I go back to the council I am told my constituent is on the list. It is not acceptable for someone with a disability, regardless of whether he or she is a private tenant or a tenant of Dublin City Council or some other local authority, to be on a waiting list. People such as the man to whom I refer should all be treated the same. However, those with disabilities are not being treated the same. Somebody needs to make a definite decision about Dublin City Council tenants. These people have been completely neglected because and are being asked to continue to live in their current conditions.

I have another constituent who lives in a three-bedroom house which Dublin City Council would love to take back tomorrow. She lives downstairs in her kitchen. She cannot go upstairs because she cannot use the bathroom. I have been trying to get her into a local senior citizens complex. She got an offer of a place but it was not suitable. The woman has lived in close proximity to other people for so long that the place she was offered would not have been suitable as a result. If at all possible, somebody from the Minister of State's Department should speak to the local authorities about how they treat their tenants in terms of installing basic facilities - such

as, for example, shower units - and the length of time people are obliged to wait.

Another constituent, whose name I will not mention, is a beautiful young man of 20 years of age who has autism and intellectual difficulties. I am embarrassed about this case. He can speak. His family has reared him to be a lovely young man. He lives in a different world. I see him every day because he lives not far from my home. His parents have been struggling since the day he was born to get him into various services. They made telephone calls, wrote letters, lobbied the authorities and did all in all in their power. Recently, after he finished in mainstream school, he was in a day care centre where he could do little work projects. He was excluded from the school because he had an altercation with one of the students and became violent. He has been out of sorts for the past couple of weeks because his medication has been changed. Somebody else is now looking after him. His family has requested that he be considered for long-term rehabilitation because there is no more they can do. They are at their wit's end. He has home help coming to the house. However, the home help runs out of the house and on to the street to get away from him. I have been in contact with the Minister of State's office, with the office of the Minister, Deputy Varadkar, and with the HSE. I have gone around the world in respect of this case. We are spending huge sums of money, more money is coming in and all that could be offered to this family in stress was a week's respite in Monaghan. I do not usually talk about intimate, personal matters because I do not like naming people. As a public representative I have come to the end of the line, like that family because unless this lad is dealt with he will either hurt himself, the people caring for him or, worse, a member of the family. I listen to other public representatives describe individual cases at every meeting here. My job, like theirs, is to deal with individual cases. I have come to a brick wall on this one and I beg the Minister of State to intervene because I am afraid of what will happen. If anything serious does happen we will all be dragged over the coals and I do not think it is worth that. The Minister of State knows the case.

Vice Chairman: Deputy Mitchell O'Connor is not here but we would appreciate an update on deaf-blindness because Carol Brill addressed the committee on this issue.

It is very significant that in the lifetime of this Government disability residential centres are being inspected on a statutory basis by the Health Information and Quality Authority, HIQA, because the services are so varied. The Minister of State is familiar with this from the nursing home sector. Now that HIQA is inspecting disability services there is a cost for them to bring their facilities up to the standard. Is there a plan for them, similar to the one the Minister of State approved for nursing homes in the past few weeks?

It would be useful to have breakdown of where the additional posts in primary care are and how they are used.

Deputy Kathleen Lynch: I will consider Deputy Catherine Byrne's request this afternoon and see how we can progress it because the Deputy has been talking about it for a considerable time. I would have thought it would have been sorted out by now.

To respond to Deputy Ó Caoláin's question about respite and Deputy McLellan's comment about the 600,000 people and the breakdown of respite hours, I would not like the message to go out that everyone who is registered as having a disability wants respite because they do not.

Deputy Sandra McLellan: I was trying to make that point.

Deputy Kathleen Lynch: Most people with a disability want their own space rather than

respite. There are people, however, who will never be in a position to live as independently as they would like and will need supports, whether in separate accommodation or not. Some have such profound difficulties that they will always need the type of wraparound service being provided at the moment in this case.

We will continue this year to maintain the amount of hours, 3.9 million, of respite. That service is being delivered to 2,300 adults. Reconfiguring service will be very important as more people come out of congregated settings. In answer to Deputy Healy, that will increase but the 84 places we are talking about are for this year. That is not the sum total of what is being done. We were hoping for 150 but as everyone is aware the resources were not available. We have the resources for next year and the transformation fund with Atlantic Philanthropies will help us to do an enormous amount. I should have included that in my opening remarks because it has allowed us to do things we probably could never have dreamed of doing.

The transformation fund of €45 million will comprise €15 million from Atlantic Philanthropies and €30 million from the Department of Health. There will be four key priorities - a transition to a person-centred model of service and supports, which is decongregation and independent or community living; developing capacity, there is no point saying we will bring people into the community unless the capacity is there to support them; and research and evaluation. I saw Last Tuesday an interesting publication from inclusion networks, which evaluated the experience of 50 people who have moved to community-based settings. The majority, not all, were very happy. It is amazing that we expect people to be full of the joys of life but they are exactly the same as us and people expect different things. The fourth priority will be to develop an advocacy framework for people with disabilities, which we have already developed for older people and which is working extremely well. Inclusion Ireland, under Paddy Connolly, is working with various groups around the country to help us develop that and that is going well.

There will be 160 registered nurses intellectual disability, RNID, qualifying this year. We are very lucky that as part of the reform in the Department, Siobhan O'Halloran is one of the directors. She looks after nursing and mental health. She has a particular interest in nursing and started her career as a disability nurse. She is very aware of the value of what a disability nurse does in the congregated settings but also in the community where we will need far more, to co-ordinate and allow people the freedom to ensure they reach their potential. Sometimes I think that we almost expect it to be our potential but that is our expectation rather than theirs.

In respect of social housing, grants and so on, I spoke on a Private Members' Bill in the Seanad last week on older people and all the same issues come up, how to maintain people in the community; reconfigure the house, the community, the outside space and so on. I do not have responsibility for any of that. I say that not to pass the buck but because I believe it should be under one umbrella. Someone who owns a home is treated differently from someone in social housing, as public representatives we all know exactly what the difficulty is. Was it Julius Caesar who said as soon as everything goes wrong, we put a different name over the door or organisation? I do not believe in doing that but I think that in the next Government and I am not certain it will happen because I do not think I have that much influence, we should have a Department of social and primary care which would take responsibility for all of that, the social needs of the person and the primary care as well. In terms of right now, inasmuch as we have been in negotiations with the Department of the Environment, Community and Local Government and the officials have met Bairbre Nic Aongusa who has a very deep and clear understanding of the disability sector. We have talked to the Department about the whole area of environment and disability. However, it is something that we have to negotiate rather than

being able to make that decision ourselves, something I hope that people will understand. It is not that we are disagreeing because we agree fully with what has been said.

I will allow Mr. Pat Healy to deal with the question on transport to day services. We have made significant progress in regard to people leaving second level education. Every year it was a crisis which those of us who have been here for a while will know. Every June and July parents stood outside the gates demanding to know where their children would go to secondary school. We have managed to ensure there is funding. Advanced planning needed to be put in place. The situation where suddenly, at the end of May, some 4,000 people would look for a place needs to be addressed. Therefore, advanced planning is crucial and that has been happening.

Deputy Neville spoke about jobs and asked whether we could increase the percentage of jobs in the public sector. Under the jobs strategy the percentage has been increased to 6%. I always viewed the 3% figure to be the floor rather than a ceiling. The public sector accepted that stance as well because it always breached its target. The new target is 6% and in some cases the public sector has already reached the target.

The excellent jobs strategy was launched by the Taoiseach recently. The collapse of the economy took us to a different space and meant we took our eye off the ball for a long time. The Department of Justice and Equality is responsible for jobs because it is an equality issue. I shall return to my point about an umbrella. Maybe we should be in that space under that umbrella. Jobs cannot just be the responsibility of the Department of Justice and Equality and the Department of Jobs, Enterprise and Innovation should play a central role.

I believe one cannot have a jobs strategy without including people with disabilities. I do not think that every one that is registered with a disability will sign on as being unemployed. The numbers will be fairly small but they could grow if we are serious about the matter. The Department of Jobs, Enterprise and Innovation and the Department of Social Protection have a major part to play in this initiative. Again, its about that umbrella and figuring out how to join up all of the pieces. In saying that, I sometimes get frustrated when I am asked questions about matters for which I have no responsibility.

Yesterday afternoon, the Minister for Children and Youth Affairs, the Minister for Education and Skills and I launched the new child care pre-school package for children with disabilities. Joining up the three Departments is an incredible piece of work. The initiative will work well but it took the three Departments to come together at official level in order to bring it together. The same outlook is needed in other areas as well but we often do not see it.

I will ask Mr. Pat Healy to deal with the questions on the capital programme. I can confirm that the capital programme is for both nursing homes and disability units. More than anything else, we are determined that the 20% of the beds supplied within the public space which is State-run will continue because we all know, despite the fact that it is sometimes delivered in workhouse style buildings, the care provided is exceptional. People are very anxious to be cared for in those settings and it is important we continue to ensure that happens. I now ask Mr. Pat Healy to deal with the capital programme and transport but he can ask someone else to reply if he thinks it is more appropriate.

Mr. Pat Healy: No, that is fine. The whole issue of graduating, school places and rehabilitation, etc., is tied in with the transport issue. On the positive side, as the Minister of State has said, 1,340 people have been supported and of those we were able to address as many as 508

from the existing capacity within the system, with an additional requirement for 832, including transport, for some of them. We try to prioritise and make sure that people link into the existing network of transport because there is quite a bit of it. Some of it is provided directly by the disability sector but also in local areas there are local arrangements and transport schemes. We try to link into such systems so that we do not duplicate a service. Where that is not possible then the provision allows for the transport cost to be part of this programme.

On the positive side, in regard to all of the placements in terms of 2015, the majority of people have been accommodated. Only 35 out of the 1,340 have not had their issues resolved at this stage. Principally, the issues are not around transport. Most of them have to do with trying to find additional capacity, which has been a challenge, particularly on the northside of Dublin. Securing appropriate capacity has also been a challenge in some locations. There was a particular issue with one provider that we are still working through. Transport has worked out well for that initiative this year.

When Members meet constituents they have heard about the broader issue of transport and not just transport for school leavers. We have prioritised transport within social care with our chief officers and it is something that we will prioritise for in 2016. We have already started work on the initiative. It is clear to us from the work that we have done with our service improvement teams, etc., on models of care that there is such a variety of transport provision that we are not necessarily getting best value. To get best value will require a more co-ordinated approach than currently happens across disability services whether it is physical, sensory or intellectual disability. Also, with the HSE's service provision, we have taxis, direct provision and local transport being provided in different locations. We are looking at how we can make that a priority in order to maximise the result for local people, make the system simpler for them and, from a value for money point of view, use the resource to best advantage, which will be a priority for us in 2016.

Members have also asked about congregated settings which, as the Minister of State has said, has transformed lives. It is the model that will transform the disability sector, particularly the old large institutional settings and principally around the intellectual disability side. We want to transform such places into a new model of service that works better for the people that we serve. We held a national summit yesterday, which is the fourth one this year and this topic was discussed in some detail. We gave a commitment we would make sure, as we start to roll out this programme in 2016, that there would be a strong communication programme. We also gave a commitment that we would fully consult with families, service users and their representatives and local communities as we progress this programme.

The Minister has announced that there will be capital funding to support the programme. It is an important contribution that will free us up and enable us to progress in a way that we have been unable to do so before. This year we had a target of 150 people to be transferred but we only achieved a transfer in respect of 84. The principle reason for not reaching our target was capital resources. I wish to emphasise that the Minister has secured additional resources but we are still working with the Department of the Environment, Community and Local Government to access that important resource, referred to by Deputy Ó Caoláin, in regard to Monaghan and the Respond housing association. We want to access the fund. We need to compile an appropriate set of guidelines between ourselves and the HSE and the Department of the Environment, Community and Local Government to access that fund because putting the two funds together will secure a much better result. An important point to make is that there are different strands across the sector. There is no one size that fits all. As the Minister of State said, there are sig-

nificant challenges in some of the large old institutional settings, many of which are run by the Health Service Executive, while others are run through voluntary providers, as we have seen in Health Information and Quality Authority, HIQA, inspection reports and so on. There is a necessity, as we progress with the transformation programme, to target the dozen or so centres where significant compliance issues arise. Moving people into the community will assist in dealing with that issue.

There is, however, a second strand - the 150 centres which do not need revenue resources but more access to capital. It is not generally about building new houses but about leasing or securing existing houses in the community and tailoring them through refurbishment and adaptation to make them fit for purpose for the people who wish to live in them. Consultation and engagement are required in undertaking this work. In the past two years much of the planning and consultation has taken place, meaning that we are not starting from a greenfield site. In these two strands much of the work has already been done.

There is a third strand - levels of complexity. Deputy Catherine Byrne spoke about a case in a community where there was challenging behaviour, as well as complex needs. There is a cohort who require additional focused supports to enable them to live the lives they choose in local communities. It is important this be done properly and it will require the capital fund to assist it. It will also require some initial preparatory work. For example, we have converted two of the bungalows at Áras Attracta to be used for eight people in preparing to move into the community next year. That approach is being replicated at other locations.

As the Minister of State announced, the capital plan has to be finalised as part of the service plan process. Our understanding is that we will be looking at a figure of €20 million next year, a significant additional contribution which will be well received in the sector, given the challenges encountered. We will be working closely with the sector in implementing the plan.

Deputy Kathleen Lynch: In the primary care sector there will be 260 additional posts, 52 of which will be in speech and language services because this is the area where there have been the greatest difficulties. It is to build up primary care teams, a process which will continue with the €20 million allocated.

We took a particular view of the waiting list for CAMHS, child and adolescent mental health services, at the start of the year. We discovered that there were over 200 who should not have been on the list and should have been dealt with in primary care services. Accordingly, we are developing a programme in child and adolescent psychological services to be delivered in the primary care sector. I admit it took a little time to get the two groups together. Now that they are together, it is incredible the amount of work they are doing. We will be delivering much of the programme in the primary care sector rather than having people move into acute units which, in some instances, are not suitable for them. This will be included in the service plan.

We have looked at the issue of deafblindness, a matter in which Deputy Mary Mitchell O'Connor is very interested. We are not inclined to have a specific definition because, if we did, there would have to be specific definitions for other conditions. It would also raise issues about the questions included in the census and the database. While there are particular difficulties around it, we are not inclined to go down that road. I realise that for people who are deaf and blind and may have additional difficulties also, there will have to be extra and specific specialised supports put in place for them.

The launch yesterday of the preschool programme took place with Child Vision and the

Learning Tree, organisations which do an incredible job in this area, not just with those who are visually impaired but also with a range of children with disabilities.

Vice Chairman: I thank the Minister of State and her officials for attending. It has been a useful exchange, one we have been trying to facilitate for some time.

Sitting suspended at 11.25 a.m. and resumed at 11.35 a.m.

Assistance Dogs in Ireland: Discussion

Vice Chairman: Our second session today is to discuss the increasingly important role played by assistance dogs in helping a range of families across our communities and the measures needed to regulate for quality assistance dogs to play a caring, therapeutic role into the future. We are joined by representatives of the Irish Assistance Dogs umbrella group, which represents a number of organisations working with assistance dogs. I welcome Dr. Louise Burgoyne from University College Cork, UCC, who is carrying out research into best practice in the area, Ms Jennifer Dowler, CEO of Irish Dogs for the Disabled and Mr. Andrew Geary, parent representative with Irish Dogs for the Disabled. I thank Mr. Geary for his assistance in organising today's meeting.

I also welcome Ms Lean Kennedy, Irish Guide Dogs for the Blind, Ms Nuala Geraghty, Autism Assistance Dogs Ireland, and Ms Sinead Dutton, My Canine Companion, who will participate in the questions and answers session after the opening statements. I also welcome some special guests in the Visitors Gallery, in particular Oisín and his dog Oscar and Olivia and her dog Fifi.

I remind the committee and our witnesses of the position regarding privilege. 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 committee. However, if they are directed by it to cease giving evidence on a particular matter and they 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 are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person or 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 Houses or an official either by name or in such a way as to make him or her identifiable.

I invite Dr. Burgoyne to make her opening remarks. She has approximately four minutes for her presentation.

Dr. Louise Burgoyne: On behalf of the Irish Assistance Dogs umbrella group, I thank the committee for inviting us to make these presentations. I will brief the committee on the current research in the sector and our work within the umbrella group. The positive effects of assistance dogs, AD, programmes have generated considerable interest and enthusiasm from care givers, service providers and researchers. I have provided supplementary information to the committee so members can refer to that for references to the published literature. Essentially, there is a need for more rigour in this evidence base and a greater clarity on the deployment of resources in this area. To this end, researchers at UCC are working within this new umbrella

group to strengthen the understanding of the impacts of AD services on family functioning.

Ireland has been at the forefront in the development of assistance dogs programmes. Launched in 2005, the Irish Guide Dogs for the Blind assistance dogs programme for families of children with autism spectrum disorder, ASD, was the first of its kind in Europe. Since then there has been a surge in development, resulting in the establishment of three more charities in the area. Our research to date with members of this group has included an evaluation of parents' perceptions of assistance dogs for families with children with ASD. Our findings indicate that they are a valuable resource for families.

On the basis of this study, we developed a protocol and we were funded by the Irish Research Council to carry out a user-led needs assessment of AD services in Ireland. The findings indicate that while the need to protect children from environmental hazards are currently being met outside the home, there is a need to sustain child safety within the home, a need for increased access to these services and a need for additional resources. There is also a role for technology in the development of AD services in Ireland. We are currently seeking funding opportunities to carry out a complete economic evaluation to estimate the costs associated with these services, the cost effectiveness and the cost per quality adjusted life year, or QALY. We have recently engaged as well with the life sciences interface group at Tyndall National Institute with regard to increasing the effectiveness and efficiency of ADs using advanced technological solutions. The committee can refer to the supplementary slides in respect of this also.

Currently there are 188 service animal interventions registered with the international standards body Assistance Dogs International, ADI. Assistance dogs include guide dogs for the vision impaired, hearing dogs for the hearing impaired and assistance dogs for people with other disabilities such as autism. I will now give the committee some definitions because it is important to clarify what kind of dogs are involved in certain interventions. There are three formal groupings of animal-assisted interventions which involve dogs. We have service-animal programmes, with which we are most familiar and include guide dogs and assistance dogs. These assist people in their daily lives and live in-house with them. We have animal-assisted activities which are delivered by trained personnel in environments such as hospitals and educational settings. A good example is a therapy dog trained to provide affection and comfort to patients in nursing homes. We also have animal-assisted therapies, which are practised by professionals, including psychologists, psychiatrists and occupational therapists, and have individualised therapy goals. The goal is on improving physical, social and cognitive functioning. An example is an occupational therapist who may work to promote fine motor skill development in a child via a series of structured tasks with a dog. A "companion dog" describes a dog that provides companionship as a pet and is akin to the family dog.

I will now pass the committee over to Ms Dowler who will talk a little further about the umbrella group charities.

Ms Jennifer Dowler: I thank the committee for having us here today and congratulate Dr. Burgoyne on her presentation. I will talk about the history of assistance dogs. Assistance dogs originated with the guide dog after First World War. Approximately 40 years ago the broader concept of assistance dogs was developed. Assistance dogs are trained to assist people with a wide variety of disabilities. We have the guide dog, which is trained specifically to assist people with visual impairment. The hearing dog assists people with hearing impairment. Assistance dogs, also known as service dogs, cover all other areas.

I will introduce to the committee the charities we represent. Irish Dogs for the Disabled

is a national charity which trains assistance dogs for children and adults living with physical disabilities so that they can achieve greater independence. Irish Guide Dogs for the Blind is the longest acting assistance dog-guide dog organisation in Ireland. It was founded in 1976 and helps the blind and visually impaired as well as children with autism and their families. My Canine Companion was set up in 2011. Its main purpose is to provide highly trained and skilled service dogs for people with autism. Autism Assistance Dogs Ireland is a national charity which trains assistance dogs for children with autism and their families. In addition to the group, the Irish Kennel Club promotes responsible ownership and breeding of dogs throughout Ireland through education, registration, training and support. In 2014 a coalition known as Irish Assistance Dogs was formed to encourage the exchange of ideas and best practice among its members, raise awareness among the general public and promote behavioural and legislative change to ensure that vulnerable clients and adults are protected within the sector.

All the groups have agreed to the standards set down by Assistance Dogs International and are fully accredited or in the process of being fully accredited. The accreditation process covers standards in the following areas: administration, client training, training of dogs, health and welfare of dogs, staff training and volunteers, facilities, prison programmes, self-certification and privately trained assistance dogs teams.

We are here today because there is a need for change in the law. Currently, all laws regarding public access pertain specifically to guide dogs for the visually impaired although keepers of assistance dogs are exempt from being prosecuted for keeping a dog on a property where food is being supplied. Our group believes assistance dog users need the same legal rights of access as guide dog users; all organisations, be they not for profit or private, must ensure that public liability insurance is provided for all qualified assistance dog partnerships upon graduation; all organisations must, as a priority, ensure the welfare and safety of both the client and the dog at all times and ensure that proper procedures are in place to address any problems that would arise in this area; all current allowances received from Revenue to guide dog users should be extended to all assistance dog users; and all assistance dogs should be exempt from the dog licence requirement, which is the case with guide dogs.

The group is proposing an individual passport-style document would be issued to each ADI certified partnership to assist in the identification of genuine partnerships. Our greatest concern is the increasing number of companies selling assistance dog-style jackets and branded materials and the ease with which anyone can acquire these items. Our fear is that insufficiently trained dogs will behave in a manner which will affect access for all certified assistance dog partnerships.

Mr. Andrew Geary: I thank the committee for its invitation to address it and Ronan and Denis for their great assistance in putting together our presentation. I am here as a parent. The first thing I will point out are the enormous benefits to a family having an assistance dog. It allows the family to behave more as a family and allows a person to socialise and go to places which may have not been possible before becoming part of an assistance dog partnership. Many trips to local restaurants or on a plane or ferry would be impossible without the assistance dog partnership. Assistance dog partnerships provide health benefits as both emotional and physical needs are met and this is evident from international and national studies.

There are two distinct groups of parents in the assistance dog sector. There are approximately 450 lucky parents who are part of an assistance dog partnership. They have received dogs from the charities represented here today. These dogs have been fully trained over the course of at least two years before being placed with the family. However, these lucky people

are facing problems they have not faced before. The problems relate to access to restaurants, public parks and transport. The problems have only come to light of late in this country because such a high standard had been set in relation to guide dogs and all assistance dog charities inherited the standard. There are a number of other issues for the lucky families. All the charities are financed through voluntary and charitable work. I help Ms Dowler's charity on numerous occasions throughout the year. This is illustrative of all parents in partnerships in the sector. Parents are out fundraising even though we all have children with a disability, be it physical or another type of disability such as autism. There are many wants and needs for those children.

There are also unlucky families who have not been able to get onto waiting lists. Charities are under pressure to produce partnerships but they must at all times maintain the minimum standards. There are at least 700 unlucky children on the waiting list in the sector. Those people are being targeted by the non-charity sector. Enormous amounts of cash have been handed over and there is no recourse for the families except that provided by contract law. All of the charities have been forced to close their waiting lists given the pressure on them. The charities cannot allow their standards to slip because those standards are international standards. We want to ensure all our dogs are accepted. I took a partnership dog to the UK last year. There was no problem with the dog's accreditation because the standards applied in Ireland were known. I ask the Oireachtas to consider this issue from a parent's point of view. We ask it to review the legislation in place and take account of practice in the English speaking world where legislation has been enacted in the equality or equal status sphere where guaranteed access is approved and penalties apply where there is a lack of access to transport and accommodation. We also ask the Oireachtas to protect the service retail industry in this context by ensuring it knows that in this sector we provide dogs trained to the highest standard to ensure it will recognise the accreditation involved in the sector.

We represent a number of disability groups. We ask the Oireachtas to focus on what is required, but there is also a need to focus on what will be required in the future. There is no hearing dog assistance charity in the Republic of Ireland. As Dr. Burgoyne outlined, there are a number of other avenues our near neighbours in the United Kingdom have examined in the medical detection field.

Vice Chairman: I thank Mr. Geary very much for his contribution. We will now take questions from members.

Senator Thomas Byrne: I have no questions because this issue is self-explanatory, but I took a great interest in Joe Duffy's recent coverage of the Service Dogs Europe issue. It was one of the best and most important examples of public service broadcasting in recent times. I do not if it has done much damage to the sector in which our guests are involved, but it has clearly done much damage to those who have been affected by it. In the light of what the Vice Chairman said, it might not be appropriate for Mr. Geary to comment as the matter may be before the courts, as I presume it is. The value of our guests coming before the committee is that it highlights the issue for the Oireachtas.

I was not overly aware of the access issues involved. If there is more information available, I would be very interested to hear about any instance privately, even if Mr. Geary is not prepared to give the information in public. I certainly was not aware that this was an issue, as I have not received complaints about it. I am, therefore, shocked to hear about it and I am not sure what we can do about it. Clearly, the sector needs a huge amount of funding. We have neighbours who are apparently on a waiting list for an assistance dog for a child with autism. People have been let down by the company in Dundalk and I do not know where we go from

here. Are there many private operators involved in this sector or are all of the operators charities? When I first heard about the issue in Dundalk, I was not aware that it was a business. I had always assumed that it was a charitable endeavour.

Mr. Andrew Geary: Luckily for us, the vast majority of dogs placed in this country have been placed by charities. However, what has happened in Ireland has been replicated in every other democracy in that when waiting lists cannot be met, this type of operator takes advantage of the situation and that is when problems with access occur. There was no problem until this year, but our service and partnerships are definitely encountering difficulties in public parks, a place where one would never expect to have a difficulty with an assistance dog, and shopping centres.

Senator Thomas Byrne: It has become an issue recently, as it is not only people who are blind who have assistance dogs.

Mr. Andrew Geary: Yes. The general public and the media have been educated that the sector is much broader than they thought. Up until now everyone thought every dog was a guide dog.

Senator Thomas Byrne: For the blind.

Mr. Andrew Geary: Everyone thought an assistance dog was a guide dog. Thankfully, very high standards have always been upheld by Irish Guide Dogs. However, everyone now knows that there are rogue operators on the island, but this has happened elsewhere in the world.

Senator Thomas Byrne: Are there other rogue operators around the country apart from the ones who have been highlighted?

Vice Chairman: I will take questions from other members and then ask our guests to respond to all of them together.

Senator Thomas Byrne: My colleague, Deputy Billy Kelleher, and, I am sure, the other health spokespersons are in the Dáil dealing with a health Bill which is unfortunate timing.

Vice Chairman: Does Deputy Seamus Healy wish to contribute, as I know he has to leave shortly to speak in the Dáil?

Deputy Seamus Healy: That is appreciated. I may have to leave as I am due to speak to speak shortly in the Dáil.

I welcome our visitors. I thank Dr. Burgoyne and Ms Dowler for their very informative presentations.

A representative called to my consistency office some time ago about this matter and made me aware of the difficulties arising in that respect. Guide dogs and assistance dogs are very important for the families and individuals who require them. What sources of funding do the various organisations represented have? Is it all on a charitable basis? Are there individual contributions or are public funds made available to any of the various organisations represented here?

Is there a national scheme to fund the training of assistance dogs and, if so, it is recognised legally? I certainly was not aware that there was a big difficulty with access, although the issue has been raised in the media in more recent times. Does the difficulty concern the number of

guide dogs and assistance dogs available?

Ms Dowler has said changes in the law are required. Has there been consultation with the Government or the Department responsible? If not, today's presentation marks the start of such consultation. I know that the committee will be supportive of the presentation made, as well as of the requests made by our guests.

Deputy Mary Mitchell O'Connor: I thank our guests for coming. It has taken me a year to get them here and I was trying to do so before the issue arose on Joe Duffy's radio programme.

I would like a member of the panel to explain how important it is for a child with autism to have an assistance dog and to talk about how the life of a family and, more importantly, the child is transformed. I do not think people understand this. I have to put up my hand and say I did not understand it - I was a school principal in charge of 600 plus children - until I saw how it had transformed a child's life in the home. People will be listening to these proceedings or may track them at a later stage. It is important, therefore, that this information be outlined for the families concerned and also on the issue of access and the problems people encounter in travelling on public transport and retail shops. We all talk about this issue but not too many really understand it.

I heard Mr. Andrew Geary being interviewed on "Morning Ireland" and what he had to say here about training hearing assistance dogs. It was new to me. I did not know about it until I spoke to him and I have spoken to him on numerous occasions by telephone. I became interested in it when one of my constituents contacted me and talked about the third issue in an article that had been submitted. It concerns the current allowances granted by Revenue for guide dogs. People with assistance dogs for children with autism do not receive the same revenue allowances as others. For the information of those listening to these proceedings who are interested in this issue, the dogs are very sensitive in terms of their diet. They have to be taken to the vet and are not a family pet. They are well trained and their diets, if not properly controlled, can completely wreck or change them.

It was not until I heard the Joe Duffy show that I realised there were other operators - the rogue operators as Mr. Geary described them. That is not good enough. It is very expensive to train these dogs and parents of children with special needs cannot afford to fork out money for something that is not going to work for them and that will cause more hassle in their lives. For the benefit of anyone following these proceedings who is interested in this issue, there is a lovely summary in an article of how an assistance dog can change the life a child with autism. It states: "As a result of the use of the dog, the child often begins paying attention to other people, sometimes even engaging and speaking to them". Children who have been uncommunicative for years can begin to make friends. For many parents, this is little short of a miracle - one that is only possible through the support of the organisations concerned. I saw that happen in a constituent's house. I saw how things were both before and after the child became attached to the dog. I could not believe it. It transformed things. It was a miracle. We want to do the best for the organisations and resolve the different issues that emerged during the summer. I am interested in how education leaders understand how a dog can transform a child's life. Perhaps the dog should be allowed in the school environs. Perhaps that is what we need to think of. I would like the witnesses to address that aspect.

Senator Colm Burke: I thank the witnesses for their presentations and all the work they are doing. It might be helpful if we could get some idea of the total number of dogs, ranging from assistance dogs to dogs for the blind. What kind of numbers are we talking about? If we

wanted to meet all of the targets, what numbers would we need to train every year from now on in respect of dogs for the blind and assistance dogs for people with any kind of disability?

In respect of a change in legislation where recognition is given to dogs for the blind but not assistance dogs, it might be appropriate for the committee to write to the Department. I presume it is a matter for the Department of Health. Have the witnesses identified the legislation that needs to be amended? Is it a case of introducing an amended Bill or do we need to introduce a range of new legislation to deal with this issue. Do other issues need to be dealt with? Rather than doing it in a piecemeal way, do we need to do it in a comprehensive way?

When one looks at the progress that has been made by the different groups in Ireland, how far behind the UK are we? It is only in the past ten years that we have moved away from the belief that guide dogs are only for people with a visual impairment. We are moving into a range of other disabilities, which has only happened in the past ten years. We are still a bit behind the UK. Could the witnesses outline the new developments that occurred in the UK in this area? It would be helpful in terms of planning a programme in this country over the next five to ten years.

Deputy Mary Mitchell O'Connor: Are we talking about legislation or the Revenue Commissioners changing some of their rules? If we want assistance dogs to be exempt from dog licensing, can this be done through the Revenue Commissioners and would it be a case of no more than the current allowances for guide dog users being extended to all assistance dogs? I would think this rule is coming from the Revenue Commissioners.

Vice Chairman: We had an engagement with the Minister of State, Deputy Kathleen Lynch, before this meeting. Reflecting on some of the questions asked by Senator Colm Burke and Deputy Mitchell O'Connor, there is no one Department that will resolve this issue. It seems that there are issues for the Department of Justice and Equality and the Department of Finance in terms of equality and the Revenue issue. The discussion with the Minister of State focused on the fact that there is no one section of Government dealing with the far-ranging issues relating to disability. This engagement further highlights the fact. Just totting up the Departments, the dog licence issue is probably dealt with by the Department of Agriculture, Food and the Marine. Could the witnesses indicate who wants to respond because there are a lot of far-reaching questions?

Mr. Andrew Geary: I will ask Ms Kennedy to address the questions regarding access and allowances.

Ms Lean Kennedy: I will not name the four dog schools again but we are coming here today as a coalition. The Vice Chairman is right in saying that this involves different Departments. Guide dogs are mentioned in legislation like the Control of Dogs Act. This comes under the remit of the Department of the Environment, Community and Local Government. Blind and visually impaired persons who have a guide dog get a guide dog allowance to feed and care for their dog. The Equal Status Acts come under the remit of the Department of Justice and Equality. People with assistance dogs have rights of access under the Equal Status Acts 2000 to 2011. We did work with the Department of Health which trickled down to the Food Safety Authority of Ireland and the Environmental Health Officers Association where they included assistance dogs for children with autism and companion dogs for people with other disabilities in their guidelines on food hygiene regulations. We have access.

Somebody asked about the UK. A similar situation pertains there. Assistance Dogs UK is

a coalition there. The Equality Act was introduced in the UK in 2010. This Act is modelled on the Equal Status Acts 2000 to 2011. The terminology is very much the same. Service providers must make reasonable accommodation for people with disabilities. They must recognise that an assistance or guide dog is essential to their owner. They are essential mobility and safety aids. As they are exempt from food hygiene regulations, there is no reason not to allow dogs. This is what we are asking for today. We are asking for assistance dogs to be formally included in legislation. In respect of the Control of Dogs Act, we have carried out awareness work with dog wardens and we have a lot of good will from them. They are looking at ways of changing local authority bylaws to include assistance dogs. We are trying to engage all the Departments to create awareness that assistance dogs, particularly dogs for children with autism, need to be formally included in legislation so that we are all reassured that families with assistance dogs will get the same rights and allowances that guide dog owners get.

We are also here to assure everyone that the four schools all meet the highest standards of training, veterinary care and grooming. We all work together and meet the same standards. I assure businesses that assistance dogs meet the same requirements as guide dogs and are just as essential to their owners. I hope this answers the questions.

Mr. Andrew Geary: I will ask Ms Dutton, Ms Geraghty and possibly Ms Dowler to answer the question of how a life has been transformed.

Ms Sinéad Dutton: We have had Oscar for four years. Before we had him, we could not go to Dundrum and today, my son is in the Oireachtas. He has just stepped outside to go to the bathroom. We travel on the Luas and visit public places. He asked for a coffee outside earlier. We were in Buswells Hotel this morning. It has really changed our lives. It is amazing. We bring Oscar everywhere. He comes on holiday with us. He goes on trips to Tesco with us. He is everywhere. He has had a huge impact on all our lives, particularly on Oisín but also on the older sibling who is 15 and who can now go to the cinema. Before that, we had to say that we could not go because it was too noisy, the lights went down, it was dark and Oisín would not be happy having people around. Now if he is unsure, you will see him. His hand will drop down and he will gently stroke Oscar. Before we had Oscar, I remember an incident in a crowded elevator where people would bunch in together. Oisín kicked out his leg at someone who was getting too close and invading his personal space. Oscar now acts as a natural barrier to ensure Oisín has that personal space.

Ms Nuala Geraghty: Ms Dutton has covered most of the benefits assistance dogs bring to families. I can only go on the feedback I get from the people who use our services, but it is really about the very simple things we take for granted like a trip to the local shop to pick up milk and bread. These activities can be very stressful for the parents of children with autism. I recall a parent telling me about the first trip to the shop with her child after the assistance dog had arrived. Her words were: "I get it now." The child was attached to the dog and could not run out onto the main road. The mother did not have to keep hold of his hand, throw her money at the cashier and run out of the shop. For the first time, she could stop, get her money out of her purse and talk to the person behind the counter before walking calmly out of the shop. It is those everyday activities which most of us take for granted that are huge for families which include a child with autism.

Safety, of course, is the most important issue. I am sure Ms Dutton will agree that parents find they are much more relaxed when they go out because the child is attached to the dog and there is no longer a requirement to hold onto the child's hand for dear life. That makes an everyday trip a relaxed event as opposed to being very stressful. Before getting the assistance

dog, a lot of parents had stop taking their children out because it was simply too stressful. In many cases, one parent had to do the shopping, for example, alone, while the other members of the family stayed at home.

An issue that needs to be emphasised is the importance of early intervention. The younger the child is when he or she gets an assistance dog, the better the results that can be achieved. We do get good results with older children, but where we can place dogs with families from the time the child is four or five years, he or she will get used to going out and may not go on to develop some of the behaviours that make it very difficult for parents to partake in everyday trips.

Mr. Andrew Geary: Dr. Burgoyne recently published an interesting research paper on the benefits of assistance dogs for families. She might outline some of the findings to the committee.

Dr. Louise Burgoyne: The use of assistance dogs is quite new to the research scene, but there is emerging literature which shows that they are a very valuable resource. To sum it up in one sentence, the dog acts as a bridge between the person with the disability and society. As Ms Dutton and Ms Geraghty explained, the dogs ground the person and allow him or her to function independently in society. I am sure Ms Dowler will give examples of how that works for people with physical disabilities.

There was a question about whether we had received funding for our study which focused on children with autism. We received a little funding from the Irish Research Council, about which we were delighted. The study involved making an assessment of parents' needs and what we found was that basic needs were being met in that the child was grounded and could not bolt. In short, the dog acts as an anchor. How it works is that the handler gives commands to the dog, the child being attached to the dog either by holding a handle or by a leash and belt system. Our study showed that needs were being met outside the home in terms of the dog being able to ground the child, prevent bolting and function as a source of calm and comfort. However, there also are needs to be met within the home, particularly in regard to safety. There is work to be done in assessing how assistance dog services might help to meet these needs.

The needs assessment also highlighted the importance of utilising new technologies. We have just started working with staff at the Tyndall National Institute to explore ideas around how we can maximise the effectiveness and efficiency of assistance dogs by using advanced technological solutions such as sensors. There is the potential, for instance, to develop a type of early warning system for parents. If a child is going to go into meltdown and the parent has not picked up on it, although most learn to pick up on it very quickly, the dog might be able to alert the parent to what is happening. We find the dogs cue on things we do not even notice. It is a question of harnessing that ability to make the dogs more effective.

In terms of the literature in general, most of it is extremely positive, as I said in my opening statement. We do, however, need greater rigour as to methodology to be used. A randomised control trial is required to show that an assistance dogs service really works. We also need to make a full economic evaluation. We are seeking funding to that end.

Ms Jennifer Dowler: At Irish Dogs for the Disabled, we do not deal with autism but solely with physical disabilities. We train two types of assistance dog, namely, a stability dog for children like Olivia who has difficulties in walking and, second, a dog for wheelchair users which is required to be able to open doors, turn on and off light switches, trigger alarms and so on. Olivia would not be able to walk down the steps today without her dog. When she came

to us for training last summer, she could only walk for about ten or 15 minutes while holding her mother's hand. Last weekend she walked 5 km. That is the difference a dog makes. We work with a lot of children who were told they would never walk and who are now walking. Moreover, their gait has improved, their heels are on the ground and they are getting stronger and taller. Our concern is for physical improvement, getting people stronger and more active in society and achieving their full potential. If somebody catches Olivia's shoulder as he or she walks by, having her dog with her means that she will not fall to the ground. If she does, she can get back up unassisted rather than have somebody pick her up.

For wheelchair users, having an assistance dog means they can get themselves out of bed in the morning if their special needs assistant does not turn up. They can turn on the light. If they fall out of their wheelchair, they can access emergency services because the dog will hit the alarm button. They can let the emergency services enter their home because the dog can open the door. We are now putting dogs into primary and secondary schools and workplaces. They are allowing people who previously could not leave their home to play a full part in society. They no longer have to worry about falling out of their wheelchair because even if that were to happen, their dog would get help for them. If they drop their wallet or keys, the dog will pick it or them up. Rather than looking at a future in which she would be wheelchair bound, Olivia can now look to a future in which she will be able to walk down the aisle to get married. That is the difference an assistance dog can make and I see it all the time with our clients. The dogs are truly life changing. Our clients are often quite sceptical initially when they get the dogs because our style of training is quite new. Many parents have faced years of seeing their children get worse and worse, their high muscle tone increase and their becoming, as a result, more disabled. When the dog arrives, the child suddenly can walk to the bathroom or around a shopping centre. It is quite a simple process in that once children start moving and walking, the stronger they become and the stronger they become, the more they move. Our clients could not conceive of being without their dogs.

Ms Lean Kennedy: Irish Guide Dogs for the Blind was founded in 1976, since when it has been training guide dogs for people who are blind and vision impaired. People know that guide dogs are essential to their vision impaired owners and it is the same with the assistance dogs we provide for children with autism. We speak to families every day who tell us how the dogs have changed their lives. As other speakers have outlined, many people were not able to go out together as a family for fear the child with autism would bolt or have a meltdown. They had to reorganise their lives completely. Sometimes a parent would stay at home with an autistic child so that the other parent could bring the other children out to do a family activity. Now the family is united because the parents do not have to think about it any more. They can rely on the assistance dog; their child is attached to it and it keeps the child safe and acts as an anchor so that the child cannot bolt. The dog is also an aid to keeping the child calm so that he or she is not over-stimulated by noise and everything that is going on in public places. We would not pick up on those things so much but children with autism are very sensitive to them. The dog gives the child confidence and calmness. Everybody in the family can get on with their lives knowing that the child is safe. It is absolutely life changing.

Mr. Andrew Geary: If I could address the question about where we are compared with the UK, I have studied the models across the world from a parent's perspective, although I am totally new to all this. Although we were number one in Europe in 2005, we have slipped off that radar. We were the first in Europe to have an autism assistance dog programme and now, as Deputy Mitchell O'Connor highlighted, the UK has 1,000 hearing dogs while we have one in the country at present, in Dublin, which was provided by a UK charity. Ms Dowler is kindly

training one as an example to prove it is possible. She has enough other disabilities to cover that it will not be part of her list.

Looking at the English-speaking world from a parent's perspective, there is a lot more protection for me if I am refused in New Zealand, Australia, Canada or the UK compared to here. The legislation there is very similar to that which was drafted here, as Ms Kennedy highlighted. It is in either the equality or the equal status Acts generally, and is piggybacked onto previous legislation. The UK put its legislation around assistance dogs in place in 2009 and it is already out of date because the country has suffered with the rogue element. Almost everywhere there is an assistance dog programme, there is a problem with it.

There was a question from Deputy Healy about numbers. We have about 650 working dog partnerships in the country, including guide dogs and assistance dogs. The demand is infinitely greater than that. We have at least 750 on our waiting lists for assistance dogs for children on the autism spectrum. Only My Canine Companion will deal with children beyond the four to seven age range. There needs to be research into whether the dog would continue to provide health and physical benefits beyond that.

I am involved with the Cork Deaf Association and other deaf charities. Going by demographics, if there are 1,000 dogs to a population of 60 million in the UK and if we divide that number by 12, we would probably need between 80 and 100 hearing dogs in Ireland. In the UK, those hearing dogs are broken down into 150 dogs for children and about 850 for adult partnerships. After guide dogs for the blind, the second biggest need internationally is for hearing dogs.

I am involved with the criminal justice system in my full-time job and I am delighted that Assistance Dogs International, ADI, is providing a very strong baseline for our charities here. They are all singing from the same hymn sheet. Two of them are formally approved by ADI and the other two are in the partnership scheme and on the way to full approval. Thanks to the Irish Kennel Club and Irish Guide Dogs for the Blind we expect to bring another expert from ADI from Europe to meet with our umbrella group in the new year. We had a conference last year which was addressed by the chairperson of the European side of Assistance Dogs International. Senator Colm Burke was present on that day.

As regards legislation, there is a need to protect parents. The standards set by our charities are so high but there is a need to protect people from going down the route of the rogue operator. According to the legislation in New Zealand, there are no recognised partnerships other than those approved by the legislature. The dog partnership charity or company has to be ADI approved, as a minimum, in order to get state permission to travel around that country.

Vice Chairman: That was my thinking on how to protect parents. As a parent myself, if I think something is going to make my child's life better, I am going to walk over hot coals to do it. If there are people listening now who are frustrated by the waiting list and see time slipping away, what should they be looking for to ensure what they are getting is what they need?

Mr. Andrew Geary: They should look for the Assistance Dogs International badge on the jackets of all our workers once the charities all have full approval. That is the minimum. They should go to a charity that has Assistance Dogs International clearance or partnership status. There are three different charities focusing on autism spectrum disorders. Parents then have to match the options to the needs of their child. Our umbrella group is hoping to come up with a joint application form in the new year. The process is in the very early stages. There is some

cross-contamination of waiting lists. If I need a dog for my child, I might have applied to three of the charities to get on all three waiting lists. We are trying to address that.

We need the State to look into formalising how an assistance dog is recognised. In some countries they even have the likes of the HSE inspect the partnership to determine if it is up to standard and whether the provider can have public rights access across the state.

Vice Chairman: My second question was about the sale of clothing with words on it. I would be interested to hear about that. Am I right in saying that people are free to sell clothing that has “assistance dog” printed on it? Such clothing could be put on any dog? That would contaminate, for want of a better word, people who have their dogs trained to such a high standard. Is this why we are experiencing difficulties with access to places such as public parks?

Are there any guidelines around assistance dogs being given access to schools?

Ms Jennifer Dowler: We have a few dogs in schools at present. We just talk directly to the schools and use the Equality Act to gain access. We are concentrating on our stability dog programme, primarily in secondary schools. They might go into a sixth class in primary to do preparation for first year in secondary school, when the children will be doing a lot of walking from class to class. There is a need in secondary school for the stability dog to get the child from class to class, to walk up and down steps and so on, and to deal with crowded corridors. It is a health and safety issue for the clients.

Assistance Dogs International is the standard. It is a very thorough standard that has to be achieved by organisations. I was talking with members of ADI during the week. Currently, only charities can become members. The organisation we mentioned earlier was obviously not a charity and it was using that as a means to say it could not get accredited because it was a private company. While ADI is trying to cut that loop out by inviting private companies to apply, it is felt that it is unlikely that many of them would reach the standard. They would have to have all provisions covered to meet all needs in terms of the client, the dogs, the breeding, the follow-up, insurance and everything to make sure the client and the dog are protected. They would have to deal with public access as well.

Vice Chairman: What is the position on the clothing issue?

Ms Jennifer Dowler: If I go onto Google, I can buy a “service dog” or “assistance dog” jacket anywhere. Anyone could buy one and put it on any kind of a dog. I could buy any kind of badge I wanted. The dogs that are probably not legitimately trained will have lots of badges on their jackets.

Vice Chairman: I thank Ms Dowler.

Deputy Mary Mitchell O’Connor: How long does it take to train a dog and how expensive is it to do so?

Ms Lean Kennedy: On the query regarding harnesses and equipment, we give all our guide dog and assistance dog owners a photo identification card which contains the Environmental Health Officer Association stamp on the back of it. We try to create awareness among businesses that if they need assurances about a dog they can ask the person for his or her identification card.

Deputy Mary Mitchell O’Connor: How long does it take to train a dog and what is the

cost in that regard?

Ms Lean Kennedy: In regard to Irish Guide Dogs for the Blind, we estimate that it costs €38,000 for us to provide each guide dog and assistance dog partnership. The guide dog or assistance dog owner leases the dog from us at a cost of €1, the purpose of which is to ensure we have an agreement in place because the dog owner has an obligation to us to maintain the dog in terms of grooming, veterinary care and so on.

On average, it takes about two years to train a dog. A puppy begins training at two months old. It is fostered by a volunteer puppy walking family-person, who is under the supervision of a puppy walking supervisor within their area. The volunteers and their puppies also attend classes. The role of the volunteer is to socialise the puppy in the context of its future role as a guide dog or assistance dog. The puppies are taken to public places such as shopping centres and are also taken on public transport so that they learn how to behave in terms of not seeking attention. They are also toilet trained and taught not to be easily distracted.

When the puppies are 12 months old they undergo six months of rigorous training at our centre in Cork. They are initially trained to be guide dogs and then mid-way through the training they are assessed to see whether they meet the criteria to be a guide dog or an assistance dog. The key difference between a guide dog and an assistance dog is that a guide dog needs to use its initiative. There are times when a guide dog will have to over-rule its owner. For instance, if a guide dog owner is at a pedestrian crossing and he or she indicates to the dog to cross the road but a car or cyclist is coming, the dog will need to use its initiative and over-rule the owner and not follow through that command. As an assistance dog is under constant control by a parent, by whom all decisions will be made, it does not need to use its initiative.

When a dog is 18 months old, we review the application list and decide which dog best matches an applicant. We must ensure that the partnership is going to work out. The chosen family then visits the centre, where they undergo residential training. For an assistance dog parent, this involves a week's training, which is then followed up with a number of weeks training in their home area. The instructor visits the family in the home area to ensure that the dog and child are happy to be attached to each other and that they are working safely and confidently together in the home area and familiar with all the routes. That support is ongoing. Similarly, we do the same in relation to a guide dog. Along with the initial comprehensive training which the dogs undergo, we also provide training for the potential owner, namely, the blind or visually impaired person or the parent of a child with autism, in relation to how the dog needs to behave in public places and how to be a mobility and safety aid to their owner. We also provide follow-up after care as well for up to six months to ensure that the partnership is reliable and working well and that the owner and the dog are working well together and are safe in meeting the standards that we have set for them. Overall, the training takes two years.

Senator Colm Burke: In regard to the conference in Cork, I thank Mr. Geary and all involved in arranging that conference. It was very useful in the context of getting people to work together. The presentation made today is proof that there is a lot more to be achieved by working together rather than as individual groups. Long may that continue. I hope the committee can be of assistance in relation to the changes being sought. This is an issue which I believe the committee should follow up on.

Deputy Mary Mitchell O'Connor: I agree with Senator Colm Burke. I would like to assure the witnesses that the committee will follow up on the issues they raised. The Chairman, Deputy Buttimer, was unable to be here for this meeting, in respect of which he sent his apolo-

gies, but I know he is very interested in this issue. I will do my best, with the assistance of the clerk, to ensure this matter is followed up.

Mr. Andrew Geary: We appreciate the opportunity to address the committee today. I thank Senator Colm Burke and Deputy Mitchell O'Connor for their work over the past year in supporting our umbrella group. I also thank Deputy Healy for his interest in our sector. It is very much appreciated.

Vice Chairman: I thank everybody who shared their experiences and stories with us today. I apologise for the small attendance at today's meeting, which is due to the fact that there is currently health legislation before the Dáil.

Following on from what Deputy Mitchell O'Connor had to say, some of the issues raised today, particularly around access, are not ones with which we were familiar. As a committee, we will contact all the Ministers who we feel have a role to play in terms of bringing about the changes required to the relevant legislation. I am sure members of the committee will also do all they can to further heighten awareness in relation to this area.

I also thank Olivia and her dog Fifi and Oisín and his dog Oscar for being here today. I was delighted to hear about the impact guide dogs are having on their lives and on their families. I propose that a transcript of these proceedings and the opening statements be forwarded to the HSE and the Minister of State, Deputy Kathleen Lynch. Is that agreed? Agreed.

The joint committee adjourned at 12.40 p.m. until 9.30 a.m. on Thursday, 26 November 2015.