

DÁIL ÉIREANN

AN COMHCHOISTE UM OIDEACHAS AGUS SCILEANNA

JOINT COMMITTEE ON EDUCATION AND SKILLS

Déardaoin, 3 Bealtaine 2018

Thursday, 3 May 2018

The Joint Committee met at 10 a.m.

MEMBERS PRESENT:

Deputy John Brady,	Senator Maria Byrne,
Deputy Joan Collins,	Senator John Dolan,
Deputy Bernard J. Durkan,	Senator Paul Gavan,
Deputy Margaret Murphy O'Mahony,	Senator Alice-Mary Higgins.
Deputy Hildegarde Naughton,	

DEPUTY JOHN CURRAN, DEPUTY FIONA O'LOUGHLIN AND DEPUTY MICHAEL HARTY IN THE CHAIR.

**Joint Meeting of the Joint Committee on Employment Affairs and Social Protection,
Joint Committee on Education and Skills and Joint Committee on Health**

Supports for People with Disabilities: Discussion

Co-Chairman Deputy John Curran: You are very welcome to this meeting of the Joint Committee of Employment Affairs and Social Protection, the Joint Committee on Education and Skills and the Joint Committee on Health. Colleagues with mobile phones are asked to turn them off or on to flight mode as they not only interfere with the meeting itself but also the recording and the broadcast of the meeting.

We are meeting today in an unusual configuration of three joint committees to discuss an issue of concern to us all, namely, the necessity to improve the supports available for people with disabilities intending to transition from education or training into employment. This arose specifically at our committee when we were looking at the issue of labour, activation and so forth and we discovered there were particular challenges for people with disabilities entering employment but also, having secured a job, retaining that job and the challenges there. It was in that context that we decided to do a module of this sort. While the witnesses today will set out some of the issues and challenges, we will subsequently meet with departmental officials to address those issues and to see if we can come up with some proposals in that regard. After this consideration, the committees might take up issues which are relevant to them and deal directly with them themselves.

I wish to specifically welcome the presence of our colleagues from the Joint Committee on Education and Skills, chaired by Deputy Fiona O'Loughlin, and the Joint Committee on Health, chaired by Deputy Michael Harty.

I would like a brief statement from my two colleagues, starting with Deputy O'Loughlin.

Co-Chairman Deputy Fiona O'Loughlin: Thank you very much, joint, joint, joint Chair, which I believe is the Chairman's title for this meeting. I really appreciate the initiative the Chairman has taken and the invitation to participate in this meeting.

I really appreciate the initiative the Co-Chairman, Deputy Curran, has taken and the invitation to participate in this joint, joint, joint meeting. As Chairman of the Joint Committee on Education and Skills, I am delighted to participate in this meeting to undertake to remove the barriers to people with disabilities in making the transition from education and training into employment.

I declare a personal interest in that I worked with Special Olympics Ireland for many years and had the opportunity to witness and experience the wonderful talents and abilities of people with disabilities. I have a brother, Cathal, who has Down's syndrome and the pride he takes in his job is equal to the pride I take in my job.

I completely understand the value of meeting together with the Joint Committee on Employment Affairs and Social Protection and the Joint Committee on Health, with the potential to ensure that our consideration is not limited to the remit of one committee, but that we can explore matters in a more comprehensive way both today and subsequently with the Department.

It is acknowledged that while there are still barriers for those with a disability who want to pursue third level education, there are fewer barriers today than ten or 20 years ago. However, it seems that the gains in removing those barriers are lost when people try to get employment afterwards. We need to consider how we can incentivise both people with disabilities and their employers.

We look forward to hearing the views of the experts present as to the extent of the problems and barriers, and the possible solutions. As I mentioned to the Co-Chairman, Deputy Curran, yesterday, I have been working with the Ceann Comhairle's office and the Houses of the Oireachtas Commission on establishing an internship for people with intellectual disabilities here in Leinster House because I believe we have to be leaders and show example. I am delighted that there will be a joint partnership with Care, which serves west Wicklow, and WALK from the Walkinstown area starting in September. That welcome development will help highlight the area.

Co-Chairman Deputy Michael Harty: I thank the Co-Chairman, Deputy Curran, for organising this joint meeting. From a health point of view the Government's response to people with disabilities is really cross-departmental because it involves the Departments of Employment Affairs and Social Protection; Education and Skills; Health; Transport, Tourism and Sport; Housing, Planning and Local Government; and Culture, Heritage and the Gaeltacht. The Government's response may need to be even broader than just this committee regarding employment. In my constituency of Clare social isolation is a huge problem, particularly in accessing transport for people to get to work and also in getting appropriate housing. The Government's response in making the transition from education to employment encompasses all those other Departments.

In my practice I have met self-employed people with disabilities who are working very well. At the other end of the spectrum I have met people who could easily hold a job but unfortunately have no means of getting there because of the lack of transport. These are very practical issues that can impinge on people's ability to get employment - not only to get education, but then actually to get employment. Those are issues we might explore in the meeting.

Co-Chairman Deputy John Curran: Colleagues will recognise that it is an unusual format to have three committees together. However, we are not looking at disability in a general way. This meeting is particularly focused on employment and retention in employment. I know there are other areas. I acknowledge the assistance of Senator Dolan in setting up this meeting. He attended the committee informally to give advice and direction on how we might pursue the issue. Before calling the witnesses, I invite the Senator to speak.

Senator John Dolan: I thank the Co-Chairman, Deputy Curran, for that. This comes from a very simple observation over my decades working that the problems, as Co-Chairman, Deputy Harty, and others have said, go across Departments and fall between Departments. Those are the kinds of things we will pick up today. The Co-Chairman, Deputy Curran, noted the unusual configuration. This kind of model of working is really needed to make progress on disability inclusion. We need to work with these other Departments to develop that kind of fluidity. I will be asking my Oireachtas colleagues to keep an eye on that. I really welcome this and the enthusiasm shown by the Co-Chairman, Deputy Curran, and his fellow Co-Chairmen. It is a good thing to do and get on with it. It required a bit of orchestration in terms of the Dáil and the Seanad. I greatly appreciate the leadership and support that the Co-Chairman, Deputy Curran, and the other two Co-Chairmen have shown. Senator Higgins invited a disability interest in regarding activation and that started us going.

On 7 March during the Dáil debate on the resolution to ratify the UN Convention on the Rights of Persons with Disabilities a number of the contributors mentioned that this conjoined working was coming up. People have a sense that it is a useful model. I am happy to leave it at that. I welcome people who have been colleagues for a long time. Senator Higgins has just arrived on cue just after I mentioned her.

Co-Chairman Deputy John Curran: I thank Senator Dolan and colleagues from all the committees. I thank them for their attendance this morning. I acknowledge that this meeting clashes with questions by Deputy Brady to be taken in the Dáil shortly.

I welcome from the Disability Federation of Ireland, Dr. Joanne McCarthy and Dr. Patricia McCarthy; and from Inclusion Ireland, Mr. Mark O'Connor. 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. If you are directed by the committee to cease giving evidence in relation to a particular matter and you continue to do so, you are entitled thereafter only to a qualified privilege in respect of your evidence. You are directed that only evidence connected with the subject matter of these proceedings is to be given and you are asked to respect the parliamentary practice to the effect that, where possible, you should not criticise or make charges against any persons or entity by name or in such a way as to make him, her or it identifiable. Members are reminded of a long-standing parliamentary practice to the effect that Members should not comment on, criticise or make charges against a person outside the House, or any official by name or in such a way as to make him or her identifiable.

I again remind people to turn off their mobile phones.

I call Dr. Joanne McCarthy, followed by Mr. O'Connor and Mr. Murtagh. As I said earlier, when we are having the debate all witnesses are more than welcome to contribute and not just those making the opening statements.

Dr. Joanne McCarthy: I thank the three Co-Chairmen for initiating this meeting. We recognise the pioneering nature of the initiative with the three committees taking time to consider how they can jointly explore issues and hopefully make improvements in the lives of people with disabilities. Dr. Patricia McCarthy, whose expertise comes through lived experience as well as research, and I are together making our submission on behalf of the Disability Federation of Ireland, DFI. I will set out the broad policy questions that the committee might need to consider on the topic and Dr. Patricia McCarthy will bring these to life by sharing her lived experience and drawing on her research.

I refer members to the paper we submitted earlier this week and we will build on that in today's conversation. I also refer to my colleague, Ms Joan O'Donnell, who presented on this issue to one of the joint committees in January. Her more expansive paper gives greater depth to the issue.

DFI is a national representative umbrella body working to make Ireland more inclusive and fairer for people with disabilities. We have more than 120 member organisations which provide support services to people with disabilities as well as working with a growing number of other organisations with an interest in securing better outcomes for people with disabilities in Ireland. DFI works to make Ireland fairer for people with disabilities. I am not going to try to reiterate what members of the committee already know. I am going to try to encourage them to think in a very particular way when looking at this issue. We know that working in silos has consequences. When the planning and delivery of health and personal social services for people

with disabilities take place in siloes, it is people with disabilities who feel the consequences. Policies that are good but in a silo sit in a vacuum and are unable to respond to the complex and often interwoven experiences of exclusion and discrimination of people with disabilities. The exclusions and daily challenges people with disabilities face cannot be resolved through the provisions and supports offered by any one Department.

While systematic responses to disability can be really useful in their own right, they often fail to appreciate that people with disabilities also experience and are open to the pressures of open labour market challenges such as precarious work. They are also subject to the challenges faced by the working poor and affected by the reality of youth unemployment. When it comes to employment and activation, people with disabilities have specific issues related to their disabilities, but they are also open to the pressures the general population experience. One of the main things the Disability Federation of Ireland would like the committee to consider is that people with disabilities are not simply defined by their disabilities. As they make up a heterogeneous group, no one answer will resolve an issue for everybody.

It might be useful at this time to take a moment to reflect on who are the disabled. In their constituencies and the work they do on committees members will have a particular understanding of who makes up the group of persons with disabilities about whom they talk. However, there are certain standards to which it is important we all come around. According to the 2016 census, there are more than 640,000 people with disabilities in Ireland. We appreciate and anticipate that this year an additional 56,000 people will be diagnosed with some disability. Some 71% of the people concerned are out of work, which is a very high rate. We know that 26.3% are living in consistent poverty. These are really stark figures and we need to take time to consider how best to plan and support the delivery of employment and activation supports in order to at least begin to address these issues.

There are other very interesting statistics into which my colleague, Dr. McCarthy, will probably delve a little further. We know that there are 250,000 students in higher education, of whom less than 6% are people with a disability who require support. People with disabilities are hugely under-represented in this area which could give them opportunities which would enable them to access employment.

To address the members of the Joint Committee on Health, we cannot ignore the interface with health. If one considers that there are 640,000 people with disabilities in Ireland but that the health service supports approximately 20,000 people with disabilities in day services and approximately another 8,000 in residential services, there is a significant proportion outside the system of support. The committee needs to consider that issue.

As I said, the statistics are stark and require reflection. Disability has shown itself to be stubborn and persistent. This is something we need to acknowledge from the outset. However, even in the face of its resilience, it is important to know that people with disabilities do want to work and explore opportunities equal to those available to their non-disabled peers. The Make Work Pay report in 2017 noted that this desire to work among people with disabilities must at all times be balanced against the risk of losing benefits, the challenge presented by the interface between Departments and services and the exhausting nature of deciding whether to work full time or part time and so on. People with disabilities are all the time weighing the pros and cons of the opportunities available to them. It is not all bad though. It is important to take this opportunity to formally note the efforts made across Departments to address these issues. The statistics are so stark that people have become genuinely committed to resolving the issues they raise. We have a comprehensive employment strategy. The three Departments have come

together and are committed to trying to work cross-departmentally to address the issues, which has to be welcomed. For more than 15 years the HEA has invested significantly in resources for students in higher education. There is also a new programme of adult day services in the HSE which is investing in new supports and models in the area of vocational training.

There are initiatives which are doing very well in their own right. However, we see some of the biggest challenges where they depend on an interface with other Departments and agencies. To take the HEA as an example, one has to be a full-time student to benefit from or access its services. As a student, one might also be successful in accessing personal assistant services to provide support in one's educational endeavours in university, but one may not be able to match it with a personal assistant service on the health side in order to live independently in digs just like every other student. Research suggests most people who receive personal assistant services from the HSE receive a service for approximately 12 hours a week. That is not a sustainable number of hours to support someone in further education.

Equally, the Make Work Pay recommendations included a really good initiative to engage with people with disabilities to find answers. They are telling us that one of the biggest problems is with the income threshold for receipt of a medical card. Even though this initiative is being driven by the Department of Employment Affairs and Social Protection, one of the biggest challenges people with disabilities face is that they will always have to weigh whether they can afford to go back to work. The cost of their disabilities may mean that they are hugely dependent on their medical card and that they cannot jeopardise it. These are just some of the examples that demonstrate why it is really important and we applaud the committees for taking the time to consider how they can jointly begin to look at streamlining some of these issues.

Because the lived experience is much more exciting than what I am telling members, I would like to give them a few things to think about throughout this engagement and, equally important, the engagement the committees will have with senior officials and when writing up their report after the meeting. We know that disability is complex, as do the members. No one Department and no one answer will shift the low rates of access and participation of people with disabilities or deal with the cost of disability or the poverty associated with it. However, there are answers which the committees can jointly begin to prioritise and on which they can move. We encourage them to think about the issues in a systemic way, which can oftentimes be a challenge. We encourage them to agree on two or three key measures which they believe would have a significant roll-on effect in enabling policies and access for people with disabilities. Some of the key issues at which the committees could begin to look - Dr. McCarthy will probably explore them in much greater detail - include how synergies could be found in the data required in each Department, eligibility criteria and how supports and services can transition seamlessly from further to higher education to training in order to stop people with disabilities from having to continuously go back and re-enter the system to try to maintain ongoing supports.

I encourage the committees to look at disability proofing generally. We are talking in specific terms about some of the disability-specific initiatives at which the committees can look. It should start with a disability proofing process that cuts across all of the work of the Departments. When opportunities are seen which should equally be of benefit to people with disabilities but where that appreciation is lacking, they should be made available. One example which is live is the provision of career guidance, of which there is a review. It is critical in supporting people with disabilities and giving them ambition to move beyond the boxes in which others sometimes put them. One should always think about building flexibility into systems

and supports. People with disabilities require that flexibility because of the precarious nature of disability and the ebbs and flows, as well as the fact that they sometimes cannot participate in full-time employment or education. Where is the flexibility that enables a person to benefit at a pace that is appropriate and relevant to his or her issues?

The Disability Federation of Ireland encourages the committees to take the time to think about disability in a systemic way and try not to see the answer as sitting in one particular programme or Department. Members should ask how we can create an interface between the opportunities and the good programmes in each Department so as to enable people to travel seamlessly. They should be looking to develop a passport for people with disabilities through education and employment. This is an opportunity do so.

Dr. Patricia McCarthy: I thank members for giving me an opportunity to speak to them. I will speak about my own personal experience and present some of the findings of research I have carried out.

I was born in the late 1960s and developed juvenile rheumatoid arthritis when aged two years. I have had two knees and one hip replaced within the space of nine months, but the condition did not just damage my joints, it also damaged muscles, causes significant fatigue and has damaged my eyesight, as it does for other sufferers. At the age of seven years, in the 1970s, attending a special school was the norm. Therefore, I moved from Cork to Dublin to board. That is where I received my primary and secondary education. I sat the intermediate and leaving certificate examinations, but ambition was not encouraged and my hopes of attending college were quashed by many within the system. Fast forward 30 years and I have obtained first class honours degrees at undergraduate level and postgraduate level. In 2014 I graduated with my PhD from Trinity College Dublin. Although my ability had not changed in the 30 or 40 years about which I have spoken, the system had developed in which I could access third level opportunities with adequate supports and accommodation to enable me to work and study within a flexible system. This proves that when such systems are in place, with many others with a disability, I can achieve at the highest level of academia. As a result, I have been able to do some part-time work within academia and believe I can contribute significantly in many areas.

There are many reasons young people with disabilities are not progressing through education at the same rate as their able-bodied peers. One is the lack of consistency in individual education plans. This is provided for in the Education for Persons with Special Educational Needs Act 2004, but the provisions have not yet been fully implemented, 14 years after the Act was brought forward. As a result, such students cannot always obtain the supports and resources they require. The lack of individual education plans means that transition planning does not take place at an early enough stage and the ambitions of people with disabilities are not taken fully into consideration. They are still considered to be less able, even within mainstream settings, as can be seen in the subjects they take and the level at which they take them, with many more taking ordinary or foundation level subjects than higher level.

People with disabilities are increasingly attending higher education, which is wonderful, but when they try to access employment, things do not always work out for them. There are many reasons for this and I will only touch on some of them today.

Inflexibility between employment and the systems within which people with disabilities are trying to work is one of the reasons. Many are trying to work within a very rigid system in employment and cannot, therefore, work full time. They try to retain some of the supports and resources they desperately need to live independently. They are not trying to scam the system in

any way but to ensure they can live independently and contribute appropriately to the economy. Many people with disabilities may only be able to take up part-time employment, but the question then arises of what level they can take up employment while retaining the necessary supports such as a medical card or rent allowance. The problem is that all of these supports have different thresholds and cut-off points; therefore, it is very hard for them to navigate through the system and know exactly what they can earn without it impacting negatively on them and without fearing that they will go over the limit and that things will start to fall apart.

The precarious nature of disability often means that while we may have an intention to work full time or part time for many years, it does not always happen and sometimes people with disabilities have to exit employment at very short notice and without being prepared for it. There is a constant fear of what will happen after that. There are very good programmes in place such as the WAM programme run by the Association for Higher Education Access and Disability to facilitate the transition of people with disabilities into employment which supports both graduates with disabilities and employers. In a programme in the school of education in Trinity College Dublin students with an intellectual disability are progressively being given the opportunity to take up employment and gain work experience in mainstream employment settings. While these programmes are valuable, they require consistency and sufficient funding to maintain them.

My own experience illustrates how things can change suddenly for people with disabilities. I suffer from significant vision impairment, but last July or August, within half an hour of getting up one morning, I completely lost my sight. It materialised that my eye had haemorrhaged, both at the front and the back. There was no apparent medical reason and, luckily, I have got a little of my sight back, but it meant attending 14 medical appointments within a two-month period. Members will understand I need the assurance of a medical card in such circumstances. As well as my eye condition, I have had other medical issues in the past 18 months that have required significant medical therapies, including physiotherapy. All of this was unanticipated by me, as I had been going along well for a time. Without flexibility at work and being able to retain supports, what would happen for someone like me?

I have also placed myself on the medical housing priority list because my needs have changed significantly in recent times. I am on the waiting list to get a guide dog as well. If I do not get appropriate accommodation in a timely manner - I am not talking about tomorrow, as that is not possible in the current climate where homelessness is a significant issue - a time will come when I will be offered the possibility of getting a guide dog but I will have to turn that down because my current accommodation is unsuitable for a dog. It is a question of balancing all of these considerations.

I seem to be filling in forms constantly for this, that and the next thing. They are basically looking for similar information, yet I have to fill one in for each Department and section. After it is sent, I do not know whether it has been received. I then hear that it has not been. I have got good at photocopying everything that I have to send so that I retain a copy just in case someone tells me that it was never received. I tell them that it is fine and that I will send a copy by post tomorrow. As any committee member who has tried to find information in these systems knows, all of this can take a great deal of effort. Fatigue is a significant consequence of my disability and some days I am too tired to do this.

One of the questions I am regularly asked when engaging with various Departments and services is why my family is not supporting me financially. I find that offensive, given that I have lived independently on my own for more than 30 years. As 52 year olds - most of the members

are probably younger, so that might not work - how often are members asked as grown adults living independently why their families are not supporting them financially? There is a mentality that someone with a disability is dependent on charity. That attitude needs to change. As such, it is great to see these committees joining together to realise that a person with a disability is trying to transition across all of these various Departments, as we are not just working in silos. The committees need to work together to ensure that someone like me and many others with disabilities get the opportunity to contribute to their fullest and to feel that their needs are being met in an appropriate manner.

Co-Chairman Deputy John Curran: I thank each Dr. McCarthy for her opening presentation. I call Mr. O'Connor and Mr. Murtagh, whom I believe will make their presentation together.

Mr. Robert Murtagh: Inclusion Ireland extends its thanks for the opportunity to address the committees. Mr. O'Connor and I will use a different structure to address the main issues facing people with disabilities in education and employment. We will also outline Inclusion Ireland's recommendations regarding each barrier and challenge that people face. We will cite statements from and examples of people with lived experiences.

For those members who are unaware of us, Inclusion Ireland was established in 1961 and is a national rights-based advocacy organisation that works to promote the rights of people with intellectual disabilities. The vision of Inclusion Ireland is that of people with intellectual disabilities living and participating in the community with equal rights as citizens and living the life of their choice to their fullest potential. Our work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

There is a chronic shortage of places for children with autism in autism classes in schools. This is especially prevalent in second level where the number of class spaces is about one quarter of that at primary level and where there are also blackspots. There is legislation going through the Oireachtas at present - the Education (Admission to Schools) Bill - that could solve this problem. Inclusion Ireland's recommendation is that the National Council for Special Education, NCSE, should have the power to direct a school to open an autism class so that every child who has this support need may attend his or her local school if he or she so wishes. Obviously, resources would have to flow to the school.

A lack of ambition and flexibility in the system starts early for someone with a disability, especially young people with intellectual disabilities. For example, there is no career guidance in special schools as it is assumed responsibility for these young people will transfer to the HSE at 18 years of age. If a person would like to try employment, training or higher education, it is unclear where career guidance may be sought.

The Department of Education and Skills is conducting a review of career guidance in schools. Special schools are not included in the terms of reference of the review, such is the lack of ambition within the Department for young people with disabilities. The review will examine the guidance services in second level, further education and higher education, but not the complete absence of a career guidance service in special schools. Inclusion Ireland's recommendation is that special schools must be included in the review of career guidance services as a matter of urgency.

Special schools are constituted as primary schools, meaning there is often little or no access to a leaving certificate or leaving certificate applied course due to an absence of subject

specialist teachers. This has a significant impact on the young person's progress. For example, Inclusion Ireland held an event on education for people with a disability aged over 18 years. One young man, Jason, presented. He attended a special school and left with no formal qualifications. Jason was linked in with a service called WALK PEER in Louth that encouraged him to pursue his dream of further education. He had a great love of computers and wanted to enrol in Drogheda Institute of Further Education on a QQI level 5 post-leaving certificate course. He could not enrol, as he did not have the minimum requirement of a leaving certificate applied. Undeterred, Jason took a year to complete a leaving certificate applied, supported by WALK PEER, and then enrolled. He graduated from the level 5 course and has now completed his level QQI level 6 in IT. Jason told us how he was hoping to enrol in a degree course in IT in Dundalk Institute of Technology.

There are other initiatives in higher education run by disability services. For example, KARE pioneered the inclusive learning initiative in NUI Maynooth. People with intellectual disabilities were supported by KARE to attend undergraduate programmes in the university. One young man told the Inclusion Ireland conference of how he was halfway through completing an arts degree specialising in his love of traditional music. Funding for the inclusive learning project has ceased, however, and the project is set to discontinue.

Many examples of good inclusive practice, as highlighted in these two cases, are founded on seed or project funding. Regardless of them being a success, they are discontinued and the learning on how to support young people with disabilities to achieve the same goals as their peers is lost. Good practice is rarely brought into the mainstream and dreams are dashed.

Inclusion Ireland recommends that people with disabilities must have access to supports to engage in mainstream further education and training. Examples of good practice must be supported and their learning incorporated into services such as Intreo and SOLAS.

When young people with disabilities leave school, they may come into contact with a guidance officer in the HSE. The only options for discussion are HSE-funded day services. As recently as Friday, 13 April, the HSE reported to the national disability inclusion strategy stakeholders group, chaired by the Minister of State, Deputy Finian McGrath, that the guidance service to support adults with disabilities had been completely depleted and, therefore, the provision of appropriate guidance and the facilitation of transition planning had been seriously curtailed. It said also that there is no cross-sectoral structure in place to support transition planning between health and education.

If a person would like to try employment or further education and training, they must look elsewhere for guidance and information and with no guidance counsellor in special schools, it is unclear where such guidance can be sought. Once a person is no longer a school leaver they are not a priority for the Health Service Executive, HSE. If employment or education do not work out the possibility of accessing HSE funded day services at a later stage is almost zero. The current situation is discouraging young people with disabilities from taking the risk of trying employment as support from the HSE will have evaporated if work proves to be a difficult option.

Inclusion Ireland recommends that as other school leavers may defer a college place if the wish, a similar accommodation must be available for school leavers with a disability in regard to HSE funded day services. I will hand over to Mr. O'Connor.

Mr. Mark O'Connor: I thank the Co-Chairpersons, Deputies and Senators for inviting us

here today. Ideally, we would have liked to have somebody with lived experience with us but, due to the short timescale, that proved difficult for people with an intellectual disability. A piece of work would need to be done in advance of something like this, so I apologise for that.

Co-Chairman Deputy John Curran: Can I interrupt Mr. O'Connor before he continues? Following today's meeting, we will be meeting with various officials but the meeting does not have to conclude with his final contribution. If there is something further the witnesses want to submit to us, I suggest they do it shortly after the meeting so that the members will be aware of it in advance of meeting various officials from the Department. I recognise the time might have been short but it was complex to try to bring it together. The witnesses should feel free to correspond with the committee after the meeting if that is something they want to do.

Mr. Mark O'Connor: I thank the Co-Chairperson.

For the 1,500 school leavers mainly with higher support needs in terms of intellectual disability and autism in 2018, the only option they will receive is a HSE funded day service and a life on disability allowance. On average, the cost of that is not insubstantial to the State; it is approximately €25,000 a year. That is what the State is investing in something we know is not good and is often exclusionary for people with disabilities.

To give an example, in the HSE's New Directions - Personal Support Services for Adults with Disabilities from 2012, which has yet to be implemented, people with disabilities were surveyed on what they thought about day services. Much of the time they said they were bored, engaged in meaningless tasks and had very little scope for progression within a day service, yet we continue to funnel people with intellectual disabilities in particular and school leavers into these services. That represents a lack of ambition.

We know from research done recently by the Walkinstown association that one of the main barriers to employment and further education is that there are very few courses at Quality and Qualifications Ireland, QQI, levels 3 and 4. Courses at this level are accessible to people with intellectual disabilities but when they access at this lower level of course, they then build up to level 5, 6 and so on as shown in the real life example given by Mr. Murtagh. The entire area of apprenticeships and traineeships is underdeveloped for people with disabilities.

At the Inclusion Ireland conference, Mr. Murtagh referenced earlier, the disability service provider from County Kildare, KARE, presented on a traineeship programme it piloted called Project Search in Naas General Hospital. At that particular time I believe it had ten or 12 young people with disabilities. It was a nine months internship period and the people on it got to spend three months in different parts of the hospital. It was training around real life jobs with ordinary people in a very ordinary working situations. Examples of excellent practice such as that are more the exception rather than the norm and with the HSE under a new direction it is something that can be pushed.

Solas is undertaking a review of training and apprenticeships. That review should include training for jobs that are suitable for people with intellectual disabilities and lead to real jobs paying a real wage. The Government agency, Employability, helps people with a disability to get jobs, and it is very good at what it does. However, it has quite a narrow scope of employability, which is to do with people who are job ready. That is a difficulty if a company wants a personal assistant, PA, or someone wants a bit of on-the-job support to get them started. We recommend that where people with a disability have a desire to work the appropriate service that will enable them to at least get into a company should be available because often we find

that can be tapered off.

Inclusion Ireland is mindful that the cost of disability is a difficulty for people living with disability. In terms of what is available to people with disabilities, when they leave school they generally enter the disability allowance scheme and nothing happens until whenever. There is little engagement from the Department. We know the Department has great ambition under Make Work Pay, which is very welcome, but even when they get into employment people with disabilities have significant costs. Those costs would include transport and simple costs such as additional heat in their homes. Someone who is a wheelchair user has the heating on 24-7 during the winter. That is a significant cost for them. When all of us go out to work, the heating is turned off. People with physical disabilities might have to buy prepared foods, pay transport costs, specialist aids and equipment costs and so on. A number of studies have put the cost of living with a disability in Ireland at between €200 and €270 per week.

There are schemes in place that we would consider to be cost of disability schemes. The now closed motorised transport grant and the mobility allowance are cost of disability schemes. They recognised the cost of getting people to work. Prior to our submission on budget 2018, we consulted widely with disabled people and the mobility grant and the motorised transport scheme came up frequently. Some people said that a priority was the reinstatement of the mobility grant, that it has left families in desperate financial distress and many disabled people in rural areas without transport. Another person said that there should be more bus routes for people living in rural areas, more frequent buses in towns and that community life is essential for good mental health and social interaction. Inclusion Ireland recommends that at least some thought be put into the establishment of a commission to examine the true cost of disability and that the advancement of the proposed Health (Transport Support) Bill should be a priority for the Oireachtas.

With regard to personal budgets, the personal budgets task force has reported to the Minister. It is very welcome that this is coming to fruition. We believe the roll-out of personal budgets will have a significant impact. A person with a disability with their own budget may choose to spend that on a PA support that will enable them to get to work, a course in their local education and training board or whatever. I do not know if this committee will have any influence but there was an exclusion of children within that, with no rationale for it. The research conducted for the task force indicated that children were included in other jurisdictions but we decided not to do that.

There seems to be a mean-spirited narrative throughout the report in that we are holding people with disabilities to account for every euro they are getting, and rightly so. Nobody is saying people should be given money and allowed go off and do whatever they wish with it but the accountability within it seems to be burdensome. If I was a person with a disability pursuing a personal budget, I would look at that report and think it was more hassle than it was worth. There were 32 individual items of training a person with a disability would need to manage a personal budget. If any of us saw 32 items of training in anything we were going for, we would opt for something easier.

I want to touch on the public sector's equality and human rights duty. All Departments and the HSE are required to have regard to that duty in all activities as provided for in section 42 of the Irish Human Rights and Equality Commission Act 2014. Inclusion Ireland encourages the Department of Employment Affairs and Social Protection, the Department of Education and Skills, the Department of Health and the HSE to ensure that all decisions and supports provided to persons with disabilities are in line with this duty. That means being proactive to ensure hu-

man rights are realised and discrimination is eliminated. We would like to see that as a priority.

Not just those of us in the room, but everyone in society must ask why we are spending so much money in this particular way. The amount spent on special education is getting closer to €2 billion. Approximately €1.7 billion is spent on disability services and then there are various social welfare supports and so on. Substantial sums are being spent, but we continue to see segregated lives and segregated training. We need to ask whether we are happy that this level of funding is going into this type of segregation. Some of the examples Robert and I have given of very good services are no more expensive to provide than poor services, of which there are quite a few. They are just better. In many situations, they are, in fact, more cost effective. I thank the committee.

Co-Chairman Deputy John Curran: I thank Mr. Murtagh, Mr. O'Connor, Dr. Joanne McCarthy and Dr. Patricia McCarthy for the opening statements. They were extensive and informative. At this stage, I will afford an opportunity to colleagues to raise issues and questions. I will revert back to the witnesses for responses. I ask speakers to confine themselves to approximately five minutes each to afford a reasonable time for responses.

Co-Chairman Deputy Fiona O'Loughlin: It will be difficult to confine myself to five minutes. I salute the witnesses for their passion for the area in which they work. It is so badly needed. Dr. Joanne McCarthy is right that we need to prioritise and focus on two or three key areas to make achievements. The education committee will absolutely look at that. Career guidance was mentioned by both Dr. Patricia McCarthy and Mr. Robert Murtagh and it is key. We shall take that on board. I am interested in what was said about the 56,000 extra diagnoses this year. Can that be broken down further with reference to those born with a disability and those who acquire one? Is there an age profile in that regard?

Dr. Patricia McCarthy is a testament to tenacity, vision and ambition. Hers is an incredible life story. Hearing of the barriers she has overcome to be where she is, it is clear that she is an incredible person and very compelling. She is completely right in relation to individual education plans. The EPSEN Act came in after the 2003 games and we lobbied strongly for it at the time. Much more needs to be done in that area and in relation to transitional planning. We will certainly take that up in the education committee. Supporting people's ambition to study is important because it leads to access to employment opportunities.

I thank Mr. O'Connor and Mr. Murtagh for sharing Jason's story, which is inspirational. I have come across situations in which young people with intellectual disabilities have done their applied leaving certificate. Their parents and schools find it difficult to get employers to take them on even for work experience for the required week. I cannot say I do not understand that in circumstances in which work needs to be done with employers to make them comfortable around it. I have taken students on and it has been a very positive experience. We need to work on that.

The witnesses are 100% right on the chronic shortage of places for ASD. In Kildare, we have 64 primary level classrooms whereas there are only 18 at secondary level. We had a situation recently at Scoil Na Naomh Uilig in Newbridge, which has a special unit. While eight young people had gone through eight years there, there were no places for them at second level with the result that three had to go back to a special school which was already full. That was the Department's response. It forced a local school to take the remaining five so the box could be ticked. There was a complete lack of forward planning. It is something we have agreed to consider as part of our committee's work programme and we hope to take it on in September.

We will certainly invite the witnesses in at that stage.

The witnesses are also 100% right about the fact that special schools are not included in the review of career guidance. I have been to Maynooth where I met some of the participants from KARE in the initiative to which the witnesses referred. Approximately two months ago, I was in Maynooth again and I spoke to leaders in the whole area of further education. They would love to continue that work. The point about apprenticeships and skills was well made as was the point about the need for courses to come in at levels 3 and 4. That is something we will work on. If the witnesses feel there is anything else at a purely educational level, I ask them to please comment later.

Co-Chairman Deputy John Curran: I thank Deputy O'Loughlin for sticking to the time.

Co-Chairman Deputy Fiona O'Loughlin: I found it very hard.

Deputy Hildegard Naughton: I thank the witnesses for their excellent presentations this morning. They outlined very well a lot of the challenges that need to be addressed. The Association for Higher Education Access and Disability has said there is a greater than 5% increase in the number of people with disabilities attending third level, which is very positive when one looks back to what it was 20 years ago. However, not everyone wants or needs to go to third level. The issue of apprenticeships was raised, for example. The witnesses have spoken very well on career guidance and its importance within mainstream schools for that transition and to allow pupils to maximise their potential, whether they have a disability or not. I take note of all that. Are there any other supports within the mainstream of primary and secondary education which would help people with disabilities to maximise their potential and assist them with that transition? I ask the witnesses to highlight any other areas.

I note Dr. Patricia McCarthy's personal experience and the fact that she is asked about family supporting her. In our experience as public representatives, it can often work against people with disabilities that they are living in the family home or are getting those supports. Of course, families care for people. I deal with younger people trying to transition from secondary school to the workplace or to third level and independent living, whether in a shared living space or not. There are housing issues, of course, and if one is living in the family, that can work against one. There is an emotional dilemma for parents who ask themselves whether their children would receive better support if they cut all ties. It is a huge issue and a valid point was raised in that regard.

There is a huge area we need to look at to support people with disabilities, allowing them to have that independent living and helping them to transition into whatever they want to do, whether it is an apprenticeship or the workplace. All of this will help them from a holistic living point of view. If there are any other supports needed within primary secondary school to facilitate that transition, can the witnesses set them out?

Deputy Joan Collins: I thank the witnesses for their introductory contributions. I read the reports before the meeting. What I hear is that people in the disabilities sector have felt the brunt of austerity over the last number of years. I have had the privilege of meeting people like Dermot Walsh. I do not know whether the witnesses remember him. He lived in my constituency and was down knocking on the door every day to tell me what people in the sector wanted and needed. I have met other great activists, including Dr. Patricia McCarthy.

There seemed to be a move in the 1990s and early 2000s towards personal budgets. There

was a big campaign then, but it was all pulled back during the austerity years. We have a situation where people in the general society are trying to pull back. I read an ESRI report on precarious employment which stated that one in four people is now in low-paid work. That trickles down to the disability sector in the context of trying to get access to the workplace and properly paid jobs. I would certainly work with the committee and the witnesses on this but I want to raise an issue that we as a committee can maybe set up a one-stop-shop to move towards the areas of health and education because I cannot understand a situation where we know from birth, where people have a disability and people can develop disabilities after that. We know as a society what needs need to be met for people as they grow into education.

Another area I am concerned about is that even within the education services, in disability there are inequalities. Some areas can access them because they are getting more services and other areas are not getting the services. I am investigating that now with some parents regarding education centres. There are a lot of areas that need to be addressed but if we take two or three. The education guidance, the guidance counsellors and autism units would be very productive if we could concentrate on that and the idea of a passport in the area of health. Why is each child not given a passport on his or her disability and the services linked around that passport. I will certainly listen, take on board what people are saying and work with the committee on that.

Co-Chairman Deputy John Curran: I reiterate that while we are identifying the issues today we will address them in front of some of the Departments. As a joint committee, we will also issue a report with recommendations so Deputy Collins should hold those thoughts she has had. We will have an opportunity to produce a report with recommendations along those lines.

Senator Alice-Mary Higgins: I thank all of the presenters for speaking and identifying so many overlapping issues. I know we have touched on some of them before. I was struck by a few patterns. The witnesses might elaborate a little on one or two of them. I refer to the transition points and what seems to happen to people around transition points. There is a question of people who may be coming out of education and then regarded that they are handing over to the HSE. There are transitions of people coming out of education, whether or not they will be linking with the Department of Social Protection and whether or not that compromises their relationship with the HSE and the health services or supports.

I am also interested in those who are not necessarily coming straight out of education, but who are coming back as adults and seeking to access education at a later stage, as with Dr. McCarthy. It is something we have looked at a lot in the joint committee on social protection around whether people are really being offered the full suite of potential options for them. It is an issue for persons who are on jobseeker's allowance but also for those who are on disability allowance because there has been a real concern on whether that full range of options is really there. I know there is the employability initiative but it is not necessarily simply for a small cohort who may already be very highly educated or skilled, but for those who are now wishing to start on a path of education or training. It would be very good to think about how we can make that transition better and how we can ensure there are more overlapping supports.

I was really struck by words that came from both Inclusion Ireland and from the Disability Federation of Ireland. The words "risk" and "fear" and the idea that people who have a disability and are choosing and making constructive choices about their lives should have this gratuitous risk or fear as well as whatever different measures they have to put in place in managing their disability, a fear that if they take a step on a path there may be a negative consequence. That was very striking and concerning. It should not feel like a risk to try for full-time employment. There should not be a fear that one might lose one's medical card. That is something

we need to look at and address and ensure that instead of risk, people are feeling support and encouragement, even when it may roll back.

When I mention transitions I am referring to when people try something and it does not work out. We have talked about the lack of quality part-time employment and employment supports being a huge issue for many with caring responsibilities but I imagine that for those with partial capacity it is an issue as well. Maybe the witnesses could comment on that question of quality part-time educational and employment options and how we can ensure that people are allowed to try and roll back without feeling they have to go right back to the start in terms of paperwork and bureaucracy.

I was very struck by the question of pilots. We have seen it across the board and it may be useful. I do not want to pre-empt our work but I want to ask for a list of the pilots and why they were not scaled up because there have been so many brilliant good practices and we see it again and again. For example, on the European Youth Guarantee, in a separate area, we see great projects and ideas tested out. Then something like JobPath is seen which rolls out on a huge scale very quickly. It is something we need to examine and get a stronger reporting on where the scalability and the plan is and show that there is a commitment, not just to having examples but to having a wide experience that is positive.

I refer to reasonable accommodation which did not get mentioned. I would like to get the witnesses thoughts on how we can frame the sense of what the understanding of what reasonable accommodation for employers and employees is and ensure that it is put in a constructive way in that segway between education and employment. I refer to the competing bureaucracies. Something that came up in a previous hearing of the joint committee on social protection was people who say they had medical appointments which they could not miss but they also had to sign in with the Department of social protection which they could not miss and it was jeopardising it. I know some people with disabilities who have a real dilemma where they are sometimes saying they will go on jobseeker's allowance even though they have a disability because they want to make sure they are given the opportunities. I mention the question of having to show availability for work yet also having to maintain a health schedule. Is there something we could do around that question of competing appointments? It could be five o'clock on a Tuesday and people might have to be in two different places.

I was glad to see the witnesses mention the public duty, equality and human rights. It is really important. I would like to hear the witnesses sense of how it has been taken on board, how it could be strengthened and how we could press for it. I mention the optional protocol in terms of the UN Convention on the Rights of Persons with Disabilities. I was really struck by the fact that every person is different. In a way, the optional protocol is what allows different people, with different experiences of disability to send a signal on how the situation can change.

I refer to the mobility grant and community life, if the witnesses could comment on that. This is maybe the missing piece here because often participation in community life is what leads to employment and maintains health. I mention personal discretion around the mobility grant and the personal budget, what it means for community life and how that links back into employment in the long term.

Deputy Bernard J. Durkan: I apologise for arriving late. We had a marathon session in our own committee yesterday so I am sorry I was not here in time for the first presentations. I thank Inclusion Ireland and I acknowledge the work it is doing in bringing an opportunity to progress and develop to the people with special needs and disabilities of one kind or another. I

used to be involved with the late Mr. Martin Naughton in part of the programme years ago. I will make two or three quick points.

This needs to be discussed. We have a situation where there is a duplication of services, maybe two or three groups, bodies, agencies and Departments trying to do the same thing and overlapping each other unsuccessfully. The area of school transport is one, with particular reference to transport to special needs classes or apprenticeships like we have in County Kildare, where spaces are available on the existing school transport which goes past the centres where the kids are going to special classes. These are apprenticeships after primary education. The children are not accommodated and to my mind it is an awful duplication. It is ridiculous to the point where it imposes on the parents, sometimes a single parent, the responsibility of bringing the child to the school to find that a bus passes by and goes in the gate at the same time with empty spaces on it. It is costing the people providing the service and the people who are in receipt of the service. It is not efficient. I believe in the maximisation of access to mainstream education for kids as much as possible. Not everybody agrees with me and I know that this has been an argument from time to time. To my mind the best way forward is the question of what is best for the child and what gives the child the best opportunity, taking into account the circumstances, the family and the parents. If there are two parents, perhaps it is easier. In the case of a single parent, one person having to do everything throws a huge burden on that parent in dealing with the situation. One woman mentioned to me recently that she was 25 years dealing with this from the time the child was born until now. The burden does not lighten. It grows. We need to be conscious of the need to intervene and intercede in a way that helps people who may find themselves in such a difficulty. The theory would be to alleviate, insofar as we can and by whatever means we can, the burden that is thrust upon the parents as a result of the child having a particular disability.

We also need to spend more time on autism. It is particularly poignant. Developing the child's awareness of the things around him or her is difficult. I refer to putting in place discreetly and without making him or her feel different the things most likely to be of assistance to that child. It is surprising at how early an age the child can get concerned and frustrated about being different. Inclusion Ireland is the expert organisation in this area, but in the available curriculum we need to be more conscious of those particular needs and try to address them. Mainstream and special educational needs should be coming together. There should be a meeting of minds to try to ensure we cater for children with special needs in the best possible, most effective and most efficient way at the same time.

Senator John Dolan: It was good to hear mention made of Mr. Martin Naughton and the late Mr. Dermot Walsh, God rest them both. It is all about people. Deputy Durkan spoke about families and the idea that the burden does not get easier. It is quite the opposite. I thought ambition and not being encouraged was a theme that came across from pretty much all of the speakers. I may not have very pointed questions but some things struck me. Project management comes to mind. It is the person with the disability and the family who have to be experts in this. It is one of the 32, 33 or 34 skills that Mr. Mark O'Connor spoke about. It is the public service, with all of its different entities, that needs to do the project management. People said that today in many different ways. All the forms are the same and they have to be gone over repeatedly to try to keep things moving.

Deputy Joan Collins spoke about austerity. It reminded me, and people might have a comment on this, that the Central Statistics Office figures early last year, I think it was, showed that poverty is getting worse for people with disabilities while at the same time, and this is good

news, things are improving for people in general. While no one is against that happening, things are pulling apart. It is not only money but also other issues. I would be interested in comments on that.

Mr. Mark O'Connor mentioned poor value for money in this country. We have more spending than investment. There is not the bang for the buck that either serves the people who pay the money into the pot or the people who are to get the services.

I refer also to comments about the employability programme. I do have a pointed question now. Was that a way of saying that was working at the wrong end of the stick, so to speak, and that it was focusing on people who are job ready? It seems to me that the real problem is all the bits needed to get people job ready.

Mr. Robert Murtagh and others made a point about there being a whole battery of supports for people going to third level, including access programmes and access officers. I am sure improvements are being made there. It strikes me that the area of further education, the old fashioned vocational education committees, VECs, or education and training boards, ETBs, as they are now called, that are around the corner and should be more flexible have no practical supports in place. I got a representation recently from a young woman who is a wheelchair user. I will not mention the college but it is a further education college. She was applying to do a media or journalism course. The college in question does have an accessible toilet but she needed a hoist in that toilet. The response she got within a month of a meeting happening - just the other day - was that the college was sorry but that was something that the young woman was going to have to sort out herself because the college was not in a position to provide that hoist.

While I deliberately do not want to mention name, rank or serial number, what I want to get at here is that there is an attitude or a culture that the system does not allow for this. I think the words used were "we are not obliged". This was mentioned by many people at this meeting. My heart sank while another part of me was getting angry, but it was mostly that my heart sunk. We are talking about a person who wants a bit of a dig out. It not as if the national development plan is going to be cut in half because of it. People might comment on that issue of attitude or culture. Other than that, I am delighted to hear and see the interest of my Oireachtas colleagues and their commitment to moving this on in various committees. It is right that the report will animate this and we will have different kind of conversation with departmental officials.

Co-Chairman Deputy John Curran: I thank Senator Dolan. Before I go back to the witnesses, I have a few comments. They were very impressive and comprehensive presentations. The witnesses will have an opportunity in a moment to respond to some of the issues raised. Both Dr. Joanne McCarthy and Dr. Patricia McCarthy talked about flexibility in respect of services. Perhaps the word might be interconnectivity of services. I was taken by something Dr. Patricia McCarthy said about having two applications in at the moment, one for a guide dog and one for housing. They are being assessed separately, yet she needs both. If they come in the wrong order, she will be snookered. She made that point very well. That is just an example. It can apply to a range of other services for different people. It came across very strongly that interconnectivity is missing.

Mr. O'Connor and Mr. Murtagh made specific points and recommendations on career guidance and education. We will take those on board. Before I hand back, I want to say that when Dr. Joanne McCarthy was talking, and this for the committee to focus on, it was mentioned that the purpose of this was affording people with disabilities better access to the labour market and employment as well as retention. There are many different issues that other committees will

take up. We will not be capable of dealing with everything at once. As we go forward, we as a joint committee need to focus, as Dr. Joanne McCarthy said, on the two or three key issues that would be enabling. That is key.

From the point of view of the work that we do, and even after today, I ask the delegates to reflect on this. If there is something they would like to put in writing to us, they should please do so. There are two public meetings in this series and the next one will be with witnesses from the Departments. We will be challenging them on the issues the witnesses have highlighted today. That meeting can be viewed on Oireachtas TV and we would be interested in the comments of today's witnesses in response to the presentations that will be made. Deputy John Brady was in the Dáil Chamber. Would he like to make any comments?

Deputy John Brady: No. I would just like to apologise. It was unfortunate that the two clashed.

Co-Chairman Deputy John Curran: I understand.

Deputy John Brady: I read through the opening statements and I will have a look over the contributions of all the witnesses. I will briefly address the statistic that 26% of people with a disability live in consistent poverty. From my perspective, as a member of the social protection committee and this being my area of work, this is enough to set off alarm bells.

Some positive moves are happening, and I welcome the Oireachtas initiatives with WALK to bring in people with intellectual disabilities, but it shows clear problems because that organisation has to fight to get funding on an annual basis. It does not know from one year to the next whether the project will be able to sustain itself. While it is welcome, it throws open huge discrepancies and anomalies in security of funding. To my eyes, the work done by WALK should be a template to be replicated throughout the State. I will not ask any questions because I do not want to prolong this any longer than it needs to be. I commend the witnesses for coming here. I commend Senator Dolan for the work he continues to do on this issue and I look forward to further meetings, hopefully, of these committees to look at this very important issue. I thank the Co-Chairman.

Co-Chairman Deputy John Curran: I acknowledge that the Deputy was in the Chamber and his interest in this issue. To make the point specifically, the Deputy spoke about WALK and issues in terms of funding. While he might not have an opportunity to debate this fully today it can be debated and it may also form part of the recommendations. One of the issues touched on today is where all the pilots are going and how they are developing. The whole purpose of a pilot is that if it is successful it should become a national scheme, and we will have a view on this. While the Deputy was not here today that point is not lost and it will be debated further.

I invite Dr. Joanne McCarthy to speak. She does not have to address all of the issues, only those on which she feels has a comment or insight, because we have four witnesses.

Co-Chairman Deputy Fiona O'Loughlin: I am so sorry, but I must excuse myself in a minute to go to the Chamber and I do not want to disturb the flow so I will make my apologies now. To clarify, project search, a similar project, is the project we will introduce in September.

Dr. Joanne McCarthy: I thank the committees and we will take them up on their offer to come back to further enhance information and support them in their deliberations. There were a lot of interesting questions and I do not know where any of us will start. I apologise if I forget or misinterpret something.

With regard to the statistics asked about by the Co-Chairman, Deputy O'Loughlin, according to the census approximately 30% of people with a disability are born with it. I will have to clarify this, but this is my understanding. What is very interesting is that one in four adults will acquire a disability. That is a stark figure. This is one we have to think about, because often when we talk about employment and transitioning we have in our heads a very set understanding of who are the disabled, and they are those who are born and growing up with a disability. Of course, they have very specific issues and very specific responses will be required, but for most people the disability is acquired. They are already in employment and have already gone through education, if they are going to do it. They are parents. The initiatives and interventions need to be very different for these people and we need to think very differently about this.

We could be speaking to any committee here today, but we would all agree that the point of transition is when disablement becomes most acute. It is significantly experienced in education. There is definitely not enough planning well in advance for transition points. Other jurisdictions begin to plan well in advance for transitioning for people with a disability when they are 13 or 14 but we do not do this here. We have demographics information. We know and we can pretty much predict how and when people will start to transition. We can predict when their needs will change. We can also generally predict the age and they types of neurological conditions in question, but we are not using what we have to hand to help inform the decisions we make.

A couple of weeks ago I went before another committee to discuss the public sector duty. It is under-appreciated at present that the public sector duty requires each Department to disability-proof public policies, procedures and budgets. What this meeting of committees will enable us to do is to stop Departments doing it in a systematic way and demand that if they are planning, through the public sector duty, to disability-proof they should make sure they also look at other Departments to see what the knock-on effects will be for others. We ask for a public sector duty and for Departments to think systemically about how their decisions have an impact on other Departments.

We always question who decides what pilots are sustained and what pilots are not. Under the make work pay programme, a significant amount of work was done on good quality engagement with people with disabilities to try to figure out what works for them. If pilots are being considered, the decisions of what should be further sustained, in terms of what should become part of ongoing options for people with disabilities, need to be determined hugely by how people with disabilities themselves experience it. Do not just have a cold top-down approach to evaluation but think about how the services are experienced. Some of the activation measures happening at present provide perfect examples. If people are not job ready they are not welcome. This tells us an awful lot, when we consider how many people with disabilities listening to the complexity of the issues we are putting on the table are really job ready at any moment in time, and how many can initiate a job and sustain it without some level of intervention, even if it is only at the initial stages. This is definitely something for the committees to consider.

A point about community life was raised. This goes a little bit beyond employment. Most people with disabilities are living in our communities. They are part of the most marginalised groups in our communities. They are living in the family home with ageing parents. They are living with acquired brain injuries in families that are breaking down as a result. They are people with significant mental health issues who are our neighbours. They are in our communities. When we think about disabilities we are not thinking about how our resources enable those people to be part of community life. A key part of this is about using mainstream resources in

these communities. The education and training boards have a huge role to play in enhancing the capacity of people with disabilities in work and education. The further education sector is a very under-appreciated enabler for our sector, and it is a hugely unappreciated connector for people into their local communities. I encourage the committees to think about this. When we think about activation employment, the costs associated with disabilities and the poverty people are in, we have to think about where people are. Most people are not in a position to go to third level education at any particular point. They are elsewhere. They are those hidden marginalised people in our communities who need to be connected to where there are genuine opportunities. I encourage the committees to think this way.

I raised the issue of the passport and, unfortunately, my colleague who is the expert in this area could not attend today because she is on annual leave - she will probably kill me. We have used the concept of a passport in terms of looking at how assistive technology is used to transition. We have used the concept that people should not have to look to go back all the time. If people come out of education and are now looking for a job their need for technology does not change. People should just transition and they should have a passport. The concept of a passport is a nice way to demand interfaces between Departments, agencies, systems and supports.

Dr. Patricia McCarthy: I want to pick up on the issue of education. I cannot remember names, but somebody spoke about what is needed at primary and post-primary level. I spoke about it briefly, and I reiterate the absolute need for individual education plans to be mandatory and done well to ensure all pupils and students have a plan worked out to ensure their expectations and ambitions are realised to their potential. They can achieve if the right supports are in place for them. They can then transition into further and higher education. We have spoken about the fact that those with a disability are increasingly transitioning on to higher education. Unfortunately, for those with sensory impairments, for various reasons they are not making that transition at the same rate as they should be, and the numbers of those with visual impairment has actually decreased year on year, in recent years. For someone like me with a visual impairment, I am horrified to think about. Much of that is due to a lack of planning in primary and post-primary education and lack of expectation in regard to them.

Another matter I wish to pick up on in regard to employment opportunities and so on, and I mentioned this briefly, relates to some of the programmes that are in place, such as the work ability mentoring programme the Association of Higher Education Access & Disability, AHEAD, runs very successfully. I spoke to the association recently and it has shown that over 70% of those who have gone through that programme have full-time employment now. I think it might even be 77% which is a very high level and it is really positive but we have to work on these.

I refer to school of education in Trinity College and the Trinity Centre for People with Intellectual Disabilities, where in the second year of a two year course student do a lot of work experience in real employment situations. A number of those who have graduated are now in full-time employment. Those programmes need to be appropriately funded and it shows that with the Willing Able Mentoring, WAM, programme as well as supporting the graduate with employment, they also support the employer in regard to issues around disclosure, appropriate supports and how best to engage with people with disabilities. Sometimes it is the fear of employers as to how they manage this and one can understand that. However, if they can see that it works, increasingly people with disabilities will be able to take the opportunities.

I refer to the idea of a passport where things can transfer seamlessly rather than having to go to another Department and another section even within the same Department where one speaks

to different people and one is sent around the houses. It is awful that it appears to the person with the disability that it is their responsibility when, in fact, it is not. It is the responsibility of others to ensure that we can access these things in an appropriate manner.

As somebody with a PhD, I feel I need another ten PhDs to negotiate and to navigate the systems I come up against on a daily basis.

Co-Chairman Deputy John Curran: Thank you very much, Dr. McCarthy. The point you finished on was well made. I call Mr. O'Connor and Mr. Murtagh.

Mr. Mark O'Connor: There was quite an array of questions, so I hope the response is not too rambling. I will address the education issues first and what can be done better there. The reason we speak about those autism spectrum disorder, ASD, units at second level is that we are speaking about community participation and so forth. We support parents in various areas of the country. Limerick would be one such black spot where there are very few ASD units. There are children in Limerick being bussed to north Cork, south Tipperary and way over to west Limerick and we are taking them out of their communities. They are not going to the birthday parties, they are not going to the football club and all of that stuff. That is why that is an important issue.

There was the question as to what we could do in regard to schools and preparing for life and work. We have already mentioned the careers guidance and I am not going to labour that issue. Is that a public sector duty? Is it perhaps a discrimination under that duty? That is something the Department would need to examine itself.

In terms of good practice, we have spoken about WALK PEER here on a number of occasions. A few of the Deputies and the Senators have spoken to it. It piloted a programme in County Louth where it goes into the special schools, meets young people from 16 years of age and starts talking about ambition. What are the students going to do when they leave school? We would have a link in with this group. It tries to anchor somebody down with a part-time job in his or her community, so that person leaves school, he or she knows what work is about, that he or she gets a few quid for work and that it is beneficial.

Our colleagues in Disability Federation Ireland, DFI, have spoken about poverty. The best way out of poverty is a job. When we speak about the joblessness, it is even more significant for people with intellectual disabilities. The national intellectual disabilities database mainly relates to people with a reasonably significant intellectual disability who are availing of some type of service. There are quite a few on that database who are looking for work. Less than 1% of the people on it are in open employment. Approximately 17% of people with intellectual disability of working age in this State are in employment. The numbers are really low.

It was mentioned that we need to work with employers which is correct. The National Disability Authority, NDA, does frequent attitudinal survey and, thankfully, this time attitudes have improved. There is still a small cohort of employers who would have a reluctance to employ someone with a disability, mainly in the autism and intellectual disability area.

Dr. McCarthy spoke about passports, especially for people who have a communication difficulty of any type, be it intellectual, physical or otherwise. The transition passport is really good. It helps them blend in somewhere a lot more quickly as regards their wants, their needs, their likes, their dislikes, etc., what they are good at and what needs to be worked on.

Education involves the schools but when one looks at the vocational end of things and at our

friends in the education and training boards, the courses are at a lower level. However, bringing this back to the public sector duty, all the supports that are available in higher education are only available at FETAC level 5 or upwards. If one is entering a course at FETAC level 3 or 4, one cannot access the fund for students with disabilities. I will give members an example. We supported a young lady a couple of years ago who attended mainstream school all her life but wanted to do hairdressing. There was no hairdressing course in the Republic of Ireland, definitely not in the north east, that was below FETAC level 5. She needed to go in a lower level to build herself up. There was something in the Southern Regional College in Newry and it was included in the fund for students with disabilities. However, because the course was at a basic level, she could not get the support she needed around transport, breaks, etc. The college said it had the people and was funded but as the course was at a certain level, she could not access it.

The Youth Guarantee was mentioned. Unusually when Ireland adopted the Youth Guarantee, it did not include young people with disabilities which was a puzzling decision. I was not aware of the lone parents. At a European level, they were included in the Youth Guarantee.

Mr. Murtagh will talk to the committee about employability. We have spoken of public sector duty. Dr. McCarthy commented that a person with a disability is twice as likely to be in consistent poverty and three times as likely to be at risk of poverty. A Department must consider what it is not doing right and it should look at what is being done. This might not just be the Department of Employment Affairs and Social Protection and there may be concerns about housing, transport or other matters. These are questions that must be asked. There was mention of the certificate in contemporary living at Trinity College, which is a course specifically for people with intellectual disabilities. I could be wrong but I believe those students are the only undergraduates in Ireland who pay tuition fees. Is that an issue for public sector duty? I do not know. Again, people in the Department need to ask themselves about that.

Community life and participation is at the heart of this and this is where a personal budget would benefit people. I have a son with autism and quite a significant intellectual disability. As a family, we have considered what he can do. He accesses a really good service during the week and we asked what we could do at weekends. We access local community events. We go to a park run on Saturday mornings. On Saturday nights, we generally go to the pub and do whatever else on Saturday afternoons. It could be anything. On Sunday mornings, we walk dogs at the local rescue centre and we go to trad sessions on Sunday afternoons. These are activities that are community-inclusive. I support him in doing that. If a young or even older person with a disability does not have that support, what is there? The community gets something back from us and we do voluntary work as well. There is an example already there for young people, namely, the youth advocacy programme, which was initially set up for young people having early engagement with the criminal justice system or at risk of that. It has been rolled out for young people with disabilities and although it only lasts a year, it gets people anchored in their communities. Perhaps it could be rolled out into other age groups as well.

With regard to transport, there are major accessibility issues and it is typified in the cohort of people with disabilities who protested about this outside the Houses of the Oireachtas. Some of them came here to address one of the committees. The United Nations Convention on the Rights of Persons with Disabilities had not been ratified at the time. A gentleman came from Donegal, where there is no accessible bus. He had the undignified experience of being lifted from his wheelchair and being put in the front seat of the bus, with the chair folded up and put in the boot. The reverse procedure occurred when he got to Dublin.

Mr. Robert Murtagh: I will answer Senator Dolan's query on EmployAbility, which Sena-

tor Higgins touched on as well. It is great that such service exists but it does not go far enough, so perhaps it is not centred around the individual needs of certain individuals. It is more centred around people being job-ready. I know from our experience, and we come into contact with many people, that such people want to get some work experience. There is no real outlet or place they can go to get this work experience and then get a job. This can be addressed in different ways. There are some good practice models of job coaching, with people going in with a person with a disability to model the tasks that the person might have in a role. The person with a disability would slowly learn the task required as part of the job. That job coaching does not necessarily require that the coach should be there for the entire term of employment. It is about giving the person with disability the supports needed in order to learn those tasks and be more independent in a job. There is nobody saying the job coach would have to be with the person all the way through. It could be phased out, leaving the person more independent in doing his or her job. The main point about EmployAbility and it does not go far enough. It needs to look more at the individual needs of people who want to get jobs.

We have not really spoken that much about accessible information so far. There are two aspects. The first relates to some of the recommendations and much of what we have said today with respect to schools, etc. There should be more accessible and easy to understand resources in schools so that people with disabilities can be more properly equipped to further their education. Similarly, in employment, there should be more accessible information supports so that employers can support employees in working well. Plenty of people who want to know what is going on in committees like this or in Departments come to us. There are plenty of opportunities for consultation but these are not in an accessible format. There are people with disabilities with much to say and who want to get their opinions across. Departments put out consultation documents or surveys but because they are not in an accessible format, people are unable to have their voices heard. It would be something for the committee to consider. There was mention of a report and plenty of people would be very interested what it would state. Perhaps there could be an easy to read section as part of the report when it is eventually published. It is something to be considered. There are clued-in people who regularly come to us and they want to know what is going on. It is about ensuring they have the information that helps them understand.

Co-Chairman Deputy John Curran: Before concluding, I thank colleagues from the various committees for their attendance. There will be another joint meeting in a few weeks. I thank the witnesses for their attendance, their informative opening statements and their subsequent replies to the issues raised. Dr. McCarthy made the point that we, as a committee, will be limited in what we can do and it is important that we focus on the two or three areas of greatest significance that would be enablers. If, subsequent to today's meeting, something crosses the witnesses' minds or they reflect on the proceedings before we meet people from the various Departments, they should please get in touch with us. We want our engagement with the Departments to be focused and specific and we want to try to achieve recommendations that will be meaningful and could be implemented to improve the situation. We will not be able to have a recommendation on every matter raised today but we will certainly have on some of them. We must ensure we can identify them clearly, address them specifically and make the recommendations. Certainly, the information given today is food for thought. The witnesses coming before the committee in future will be aware of the contents of today's meeting and this is not about trying to catch people out. It is about getting informed responses on the issues. If there is anything that the witnesses think of between now and the next meeting, and subsequent to that meeting and the Departments' replies, they should feel free to correspond with the committee.

The joint committee adjourned at 12 noon *sine die*.