

# DÁIL ÉIREANN

## AN COMHCHOISTE UM OIDEACHAS, BREISOIDEACHAS AGUS ÁRDOIDEACHAS, TAIGHDE, NUÁLAÍOCHT AGUS EOLAÍOCHT

## JOINT COMMITTEE ON EDUCATION, FURTHER AND HIGHER EDUCATION, RESEARCH, INNOVATION AND SCIENCE

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*Dé Máirt, 20 Aibreán 2021*

*Tuesday, 20 April 2021*

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Tháinig an Comhchoiste le chéile ag 12.30 p.m.

The Joint Committee met at 12.30 p.m.

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Comhaltaí a bhí i láthair / Members present:

Teachtaí Dála / Deputies	Seanadóirí / Senators
Rose Conway-Walsh,	Aisling Dolan,
Alan Farrell,	Pauline O'Reilly.
Carol Nolan,	
Jim O'Callaghan,	
Pádraig O'Sullivan,	
Donnchadh Ó Laoghaire,	
Aodhán Ó Ríordáin.	

Seanadóir / Senator Fiona O'Loughlin sa Chathaoir / in the Chair.

## **Business of Joint Committee**

**Vice Chairman:** Today's public meeting is being held virtually through Microsoft Teams. Apologies have been received from the Chairman, Deputy Paul Kehoe, who cannot be here because of a family bereavement. Senator Rónán Mullen will view the meeting from outside the precincts of Leinster House. I remind members to ensure their mobile phones are switched off for the duration of the meeting as they interfere with the broadcasting equipment even when on silent mode. The draft minutes of the meeting of 13 April 2021 have been circulated. Are the minutes of the meeting agreed? Agreed.

### **Provision of Special Needs Education: Discussion**

**Vice Chairman:** The next part of our meeting is with AsIAM, Down Syndrome Ireland, Inclusion Ireland and the Ombudsman for Children, Mr. Niall Muldoon. On behalf of the committee, I welcome Mr. Adam Harris, CEO of AsIAM, and Ms Nicola Hart, head of member services of Down Syndrome Ireland. From Inclusion Ireland, I welcome Ms Lorraine Dempsey, interim CEO, and Ms Margaret Turley, both of whom have presented to the committee previously. I also welcome Dr. Niall Muldoon, the Ombudsman for Children.

The witnesses are here today for a round table discussion on the provision of special needs education, with reference to the implementation of the Education for Persons with Special Educational Needs Act 2004, the EPSEN Act, something on which the committee has made a priority. The format of the meeting is that I will invite Mr. Harris, followed by Ms Hart and then Ms Turley and Dr. Muldoon, to make brief opening statements to be followed by questions from members of the committee. Each member has a six-minute slot to ask questions and for the witnesses to respond. As the witnesses are probably aware, the committee will publish the opening statements on its website following the meeting.

Before we begin, I remind members 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. As the witnesses are giving evidence remotely from a place outside of the parliamentary precincts and, as such, may not benefit from the same level of immunity from legal proceedings as a witness who is physically present, they have already been advised that they may think it appropriate to take legal advice on this matter. The witnesses are reminded of the long-standing parliamentary practice that they should not criticise or make charges against any person or entity, either by name or in such a way as to make him, her or it identifiable, or otherwise engage in speech that might be regarded as damaging to the good name of the person or entity. Therefore, if their statements are potentially defamatory in relation to an identifiable person or entity, they will be directed to discontinue their remarks. It is imperative that they comply with any such direction.

I now call on Mr. Adam Harris to make his opening statement, which will be followed by the statements of Ms Hart, Ms Turley and Dr. Muldoon. They have three minutes each. Ms Turley's statement is particularly important so I will give her a little longer, with the indulgence of my colleagues on the committee. I now hand over to Mr Harris.

**Mr. Adam Harris:** I thank the committee for its invitation to present to it today on this important topic. I also thank committee members for engaging with us on this important topic

in recent times. This is an imperative issue for our community that touches on many aspects of the education system. It is challenging to cover everything in the opening statement but I will follow up with further documentation for members after today's meeting.

AsIAM is Ireland's national autism charity and we are working towards an Ireland where all autistic people can be accepted as they are. One in 65 people in our school system today has a diagnosis of autism. Of these young people, 14% attend special schools, 21% are enrolled in a special class attached to a mainstream school and the majority, that is, 65%, attend mainstream classrooms with their neurotypical peers.

It is worth considering what children with disabilities and autistic students face when it comes to accessing the right to education. For the vast majority of children and families, seeking access to an appropriate school place is something they can take for granted but for many of our families it is the first of many battles, as we have seen recently in Cork where a significant number of young people do not have a suitable secondary school place for September. Securing a school place tends to be just the start of a series of battles to get the support and understanding needed and to have an opportunity to learn in the school environment. The EPSEN Act was set up to try to address many of these issues. Its lack of implementation has meant that they have persisted. Not only that but very often families have been without a formal voice in the educational journey of their children.

It is important to recognise that many children who are now integrated and involved within mainstream school were not only a short time ago. It is not that long ago that there were even efforts not to recognise the right of all children with disabilities to an appropriate education. However, we should not confuse this with inclusion. We will not have achieved an inclusive education system until every child is able to attend a school and to have the opportunity to learn fully, and it seems we are still, unfortunately, a long way from that point. We believe it is absolutely imperative that the Department of Education take a rights-based approach to providing supports for students with additional needs. The rights of students and the voice and experience of students with additional needs must be at the centre of this process, and we do not think non-statutory supports or approaches go far enough. If we need to see evidence of that, we need only point to the shortfalls, the lack of supports and the experiences of too many young people that have persisted across the country. We remain convinced that the only way to ensure that children have the support they need and that schools are appropriately resourced and supported is to put in place statutory supports and mechanisms as proposed by the EPSEN Act 2004.

We think this needs to take place through a number of steps. First and foremost, we would like the committee to commence a legislative review of the Act. We recognise there are parts of the Act that need further amendment to bring them into line with the UN convention prior to their implementation. We also recognise that some areas of the Act, if they were appropriately resourced, could be implemented now. We would therefore like the committee to conduct a review to identify where the Act sits within our current education system and to make a plan for it. We welcome the fact that the Minister of State, Deputy Madigan, has indicated an openness to updating and amending the EPSEN Act. We would like the committee, on foot of its legislative review, to propose an amended version of the Act and to bring that forward to the Oireachtas for passage and implementation. We think it is very important that any commencement of the EPSEN Act is accompanied by the required resources and a clear roadmap with times and deadlines for how that will take place.

Finally, legislation is a key part of how we create an inclusive education system but it must go hand in hand with cultural change. As we have seen in recent times, too often families and

students with disabilities have faced an adversarial system. Our education authorities must place the voices of families at the centre of every stage of the decision-making process, from the individual journey to the overall policy platform. It is very important that our education authorities become collaborators, not gatekeepers. I thank the committee and I look forward to members' questions.

**Vice Chairman:** I appreciate that, as you said, Mr. Harris, three minutes is a short time in which to cover such a wide topic, but you have done extremely well. I now turn to Ms Nicola Hart, who is head of member services with Down Syndrome Ireland. Ms Hart, the floor is yours.

**Ms Nicola Hart:** I thank the committee for the opportunity to present. I wish to echo a lot of what Mr. Harris said. An inclusive society begins with inclusive education, but inclusion is much more than just physical presence. According to the UNCRPD, inclusion is a process of systematic reform embodying changes and modification in content, teaching methods, approaches, structures and strategies in education to overcome barriers and provide all students with an equitable and participatory learning experience. For children with Down's syndrome, research has consistently found that academic progress and achievements are better among those children attending mainstream school. The majority of children with Down's syndrome now enrol in their local primary school, with increasing numbers progressing to mainstream post-primary school. This is a welcome development and in line with education policy. The EPSEN Act states that children with special educational needs should, wherever possible, be in an inclusive, mainstream environment with their peers.

Shockingly, however, 17 years later EPSEN has yet to be fully implemented. The Irish State has an unfortunate history of introducing legislation which is then not fully implemented, and often those sections left unimplemented are those which would have the greatest impact. The failure to enact the provisions in the EPSEN Act relating to an individual right to assessment and an individual education plan, IEP, denies students the statutory right to the educational supports needed to enable them to benefit from an inclusive education. While in many cases teachers are willing to devise IEPs, this is not universal. Schools are "encouraged" rather than obligated to provide an IEP. Assessments may or may not be available. We have long campaigned for EPSEN to be fully enacted and adequately resourced in order that the rights of students with additional needs are enshrined in law rather than dependent on "encouragement" from the Department and the goodwill of schools and teachers.

We are aware that education theory and practice have moved on since 2004 and we understand the calls for a full review of EPSEN before it is fully enacted. However, we are looking for action now, not in another decade or two. We acknowledge that there may be a need for amendments but we believe that the rights-based approach within the EPSEN Act needs to be rapidly adopted and the resources provided to do this properly. We are not looking for a repeat of the early years assessment of need process, whereby statutory obligations are often not met and identification of need brings no obligation to provide support. We are looking for students to have statutory access to individualised plans and supports which have been identified as necessary for their education. With the year that is in it, we are also calling for additional SNA and resource teaching support to be provided to students. We all know that students with additional needs have been badly impacted during the pandemic. These same students will need additional support to continue their learning. The practice of sharing access to SNAs across different classes is difficult to manage at the best of times and completely inappropriate in a pandemic. It needs to stop. We would also like to know whether the Department is gathering

information and monitoring the use of reduced timetables in schools. All children have been impacted by reduced access to education during the pandemic, but the fact remains that children with disabilities were disproportionately affected by reduced school days or weeks long before Covid-19. We have raised this with the committee before and we were assured in early 2019 that there would be monitoring of the use of reduced timetables and consultation on the issue.

To summarise, we call on the Government to amend and implement EPSSEN without delay; to provide adequate resources and training for teachers so they can provide individualised education planning; and to provide additional resources in order that any needs which are identified in the planning process can be met. We would also like confirmation that the extended school year programme will be available to all students who have Down's syndrome. We would like to end the practice of shared SNAs for children in different classrooms. We would like reassurance that the Department is monitoring use of reduced timetables in schools over and above the pandemic-related closures. We would like the Department to work with organisations and schools to develop parameters to ensure that reduced timetables are used for the shortest possible time and only for very explicit reasons.

**Vice Chairman:** Thank you, Ms Hart. I now move to Inclusion Ireland, on behalf of which Ms Turley will speak. She is joined by Ms Lorraine Dempsey. I congratulate Ms Dempsey on being appointed interim CEO of Inclusion Ireland. She gave many presentations to the previous committee on the perspective of a parent of a child with special needs. She was an inspired choice. I wish her well, and we look forward to engaging with Ms Turley.

**Ms Margaret Turley:** Inclusion Ireland welcomes the opportunity to address the committee. When the EPSSEN Act was passed in 2004 as a central pillar of the national disability strategy it was seen as groundbreaking in putting inclusive education on a statutory footing and providing for children to have their education needs assessed and met. The EPSSEN Act promises not only educational equality but also a legal obligation to deliver that education in mainstream settings, where possible. Seventeen years after the Act was passed, the main pieces of the Act that benefit disabled children have yet to be commenced. The sections of the EPSSEN Act not commenced include the parts that would give children a right an educational assessment of their needs; the development of an IEP based upon this assessment; the delivery of the education supports detailed in the plan; and an independent appeal process. In short, this means that a child with a special educational need does not have a legal right to an assessment of that need or to have such an identified need addressed through an IEP. Parents have no legal right to have an input into the IEP. Because the Act has not been implemented, children's rights are at the whim of policymakers, changes in Government, funding priorities and other factors. Recent Governments have only committed to implementing EPSSEN on a "non-statutory footing". Of all changes to education supports in recent years, there has been no move to give children a right to assessments and IEPs under the Act.

Section 2 of the EPSSEN Act places inclusive education on a statutory footing but allows for exceptions to an inclusive education provision. We also need to be mindful of the rights of children under the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD, which has been ratified by Ireland since section 2 was commenced. The UNCRPD calls for inclusive education to be provided for without exception, putting section 2 at odds with the convention.

For Ireland to move towards a fully inclusive education system where children can attend their local school with the appropriate supports, the Government needs a longer term plan that considers the following. There must be a review and commencement of the EPSSEN Act; the

Government should put forward a multi-annual, fully costed plan for moving towards an inclusive education model of education; and the Government should invest in teaching and special needs assistant resources, with class sizes needing to get below 20 pupils at a minimum. We must ensure initial teacher training has a more robust inclusive education component and that all current teachers without continuous professional development in special education are freed to complete mandatory training on this subject. Schools must be supported by fully resourced mental health and disability teams and they should be fully accessible physically, include sensory spaces and be designed with sensory processing in mind. We must engage all stakeholders in the process of developing an inclusive model to include families, educators, therapists and pupils, etc. A campaign should also be launched to address many of the negative attitudes that exist around disability in Ireland, as a sizeable minority of the population does not see mainstream schools as the place for disabled children.

**Dr. Niall Muldoon:** I will try to shorten my statement. I thank the committee for the invitation to appear before it. As members of the committee are aware, the Ombudsman for Children's office is an independent statutory body, established under the Ombudsman for Children Act 2002, as amended. The rights and welfare of children with disabilities have been a strategic priority for my office since 2016 and we are committed to continue pursuing the progressive realisation of the rights of children with disabilities.

In October last year, we published a report called Unmet Needs, which sets out the challenges experienced by children who may have a disability and require an assessment of needs, AON. The report proposes actions that we believe should be taken to address these challenges in a child-centred, rights-based manner. Our Unmet Needs report raises serious concerns about ongoing violations of the rights of children with disabilities due to significant delays for children in accessing an assessment of need, despite the HSE's legal obligation to commence this within three months of receipt of a child's application.

As members of the committee know, in September 2004, when the Government launched the national disability strategy, it was envisaged this would lead to an equitable reconfiguration of disability services. The Disability Act 2005 and its counterpart, the Education for Persons with Special Education Needs Act 2004, were key elements of that strategy. The 2005 Act provides for an AON in order to determine the health services required by a person with a disability. The EPSEN Act provides for an assessment of special educational needs so that a child with such needs may be educated in an inclusive environment. While the 2005 Act has been commenced in full, sections 3 to 13 of the EPSEN Act have not been commenced, and that is why we are here today. In the absence of a procedure under the EPSEN Act, students who require such an assessment have been applying for an AON under the 2005 Act. This has placed further pressure on the 2005 Act mechanism, which is run by the HSE.

Furthermore, in our view, provisions in the 2005 Act concerning children are insufficiently rights-based or child-centred. Accordingly, we made a key recommendation in the Unmet Needs report that "an independent expert group should be established to review the 2005 Act, having regard to the EPSEN Act, and related legislation which impacts the provision and delivery of AONs and special educational needs assessments." We recently wrote to both the Minister for Children, Equality, Disability, Integration and Youth, Deputy Roderic O'Gorman, and the Minister of State, Deputy Anne Rabbitte, asking them to initiate a review of the Disability Act while having regard to the EPSEN Act. Therefore, I noted with interest the meeting of this committee last week, at which it was reported that the Minister of State at the Department of Education, Deputy Josepha Madigan, had indicated a desire to review the EPSEN Act and the

Department of Education committed to doing that. This suggests that there could be an alignment that could at last create a better and more co-ordinated legal framework to support our children with disability from the cradle to the end of their education journey.

Earlier this month, my office published research called Mind the Gap, which we commissioned from NUI Galway to examine what obstacles in laws, policies and programmes the State places in front of children with disabilities. This research broadened and deepened our understanding of the barriers that children with disabilities in Ireland face when it comes to enjoying their rights. Unfortunately, the overarching conclusions reached are stark. Children with disabilities are not seen and they are overlooked in many child and disability-focused laws, policies and programmes. Those same children are not heard and they are not actively or effectively involved in consultations on many existing laws, policies and programmes affecting them. Children with disabilities are not counted because they are relatively invisible in data. If the State is to fulfil its duty to realise the rights of children with disabilities, it must see, hear and know these children.

Having set out the huge disadvantages and barriers that hamper the life of every child with disabilities, it is important to acknowledge that the impact of Covid-19 has been seriously and disproportionately negative for this group as well. We are here today to discuss the EPSEN Act and special needs education but it is vital to also be aware of many other issues that are live for children with disabilities and their families. With education, these issues include school places and planning for same, reduced timetables, suspensions and expulsions, expansion of the summer programme and school nurses in special schools. I thank the committee for its invitation and its time. I am happy to answer questions with the assistance of my colleague, Dr. Karen McAuley.

**Vice Chairman:** Dr. Muldoon correctly mentioned a number of matters we will get to but in today's meeting we will just deal with the EPSEN Act. Members have six minutes within which to pose their questions and receive an answer. If members wish to put a question to a particular witness, please do so, but they can also put general questions.

**Senator Aisling Dolan:** I thank all our contributors today for the breadth of contributions from many different groups. I am based in Ballinasloe and from the Roscommon and Galway area so I am very much aware of the lack of capacity for children with special needs, particularly in Ballinasloe. It is an area very close to my heart as we try to fight for places for children in special schools and additional accommodation. It is vital, particularly for children going to school in September. We are fortunate as we got some additional accommodation recently and now have two more classrooms for children in the area for September.

The voice of the advocate is crucial and in that regard I welcome Ms Turley. It is a challenge to speak to a large group but it is really important for us to hear voices like hers and listen to them. She mentioned several matters on behalf of Inclusion Ireland. I am conscious there has been a period since enactment of the EPSEN Act and a number of matters remain outstanding. This year, we have welcomed the fact that more than €2 billion, or over 20% of the education budget, has been allocated to special educational needs. I know it probably has to make up for the shortfalls in previous times but we are looking for advances to be made quickly. The Minister of State, Deputy Madigan, has looked to review this as well.

I will ask Ms Turley about her experience. Ms Turley mentioned class sizes and teacher training. What might the inclusive nature of the new teacher training that has been mentioned involve?

In respect of mental health and disability, I am a member of the Oireachtas Joint Sub-Committee on Mental Health. Are there any points the witnesses wish to make on that? Mr. Adam Harris spoke to us last week at a meeting of the mental health sub-committee and it was really powerful. Regarding this issue, I know it is looking at amending the Act to take into account more recent developments. What recent developments relating to autism should be included in it as an amendment?

I thank Dr. Muldoon for his contribution. He mentioned a number of different items, including unmet needs and in particular how there is a waiting period for assessments of need because it has not been developed and we do not have a statutory basis for a number of other areas. I do not know if he has any figures relating to that. I am curious about assessment of need. Are there any other comments he wishes to make on that?

**Ms Margaret Turley:** The training that would be good would involve getting people with disabilities into mainstream schools to see what the individual pupil needs and not saying “oh you have a disability. Okay we know what you need.” It would involve talking to the parents and seeing what would help the child to learn, what the school can do and what the parents can do to help at home, because they are trying to work together to help the child. Perhaps there could be training for teachers in order that they would know in advance what would be needed.

**Ms Lorraine Dempsey:** We have significant concerns about teacher training. This is something that has been expressed by teaching bodies and teachers. They feel ill-equipped. For example, with the establishment of so many special classes over the past several years, quite often, rather than being the teacher with the most experience, it is the teacher with the least experience who goes into the special class. I understand the National Council for Special Education, NCSE, gave directions through the Department of Health that this is not a practice that should happen but in terms of teachers being released for training and substitution cover, there is a significant issue with the take-up of inclusive training modules outside core teacher training. Were we to look at a genuinely inclusive education system, teacher training, from the point of view of a newly qualified teacher coming out of school, should be well-equipped to differentiate the curriculum regardless of the level of disability. Until we get to that point, we will still end up with a segregated or integrated education system where children will not have the option of going to their local schools because of the barriers set out in section 2 of the EPSEN legislation. If it is not in the best interests of the child or other children, that child might be denied a school place in his or her mainstream school.

**Vice Chairman:** That point is well made.

**Mr. Adam Harris:** There are a number of areas where we think the Act could be enhanced. Perhaps at a very high level, there are a couple of key examples. I echo the point made by Ms Dempsey about the need to make sure that there is nothing in the Act preventing somebody from accessing his or her school if he or she wants to. That said, we still recognise the need for a range of options and that our system is not at a place yet where all children are able to attend their local school but we believe that option should rest with families.

One thing that is missing from the Act is the voice of the child. While there is a lot of emphasis on the voice of the parent and family, it is now more critical than ever that we really listen to the lived experience and place that at the centre of individual education plan, IEP, planning and planning for future education.

One of the learnings from the Disability Act is that a lot of language within the EPSEN Act

does not really commit to concrete timelines or supports. We need to tighten that up so it is very clear when things should happen and that we are taking a rights-based approach.

It is important that we recognise that this is a highly diagnostic and medical model-driven item of legislation and that not every child with additional needs fits into clear diagnostic criteria. There are children within the autism community who must go private because of the huge waiting list to access assessment. This means that families who cannot afford to go private can lose out, so there is a need to balance diagnosis and need to make sure it is as equitable as possible.

**Dr. Niall Muldoon:** Regarding assessment of need, we do not have specific numbers but the key issue for me is the fact that the HSE reckons that it can only do 9% of assessments of need within the legal statutorily obliged timeline. This leaves 91% of our children waiting for far too long. The point I was making is that people are trying, through assessments of need, to access services they should get through the EPSEN Act if it was up and running. Parents go there because they have nowhere else to go. That is the problem. We have not created the system the way it should be created. To fair, setting up the EPSEN Act and the Disability Act in 2004 showed a real foresight into how we would want it to be. We now need to follow through on that.

**Deputy Pádraig O’Sullivan:** I will do my best to address my questions to the appropriate people but there is such a broad depth of knowledge among the witnesses, it might be difficult and a few people might want to give their input. My first question concerns IEPs, which a number of people mentioned in their submissions. Coming from an educational background, I came from a school where IEPs were implemented as part of standard practice. I acknowledge it might be a bit hit-and-miss in other schools across the country. Is there any reason why schools should not be doing them? There seems to be a reluctance in certain quarters. Is it the case that there might a reluctance to implement them because of the lack of a statutory footing? At the same time, should we not be advocating for their widespread use as part of good practice in schools? Could one of the witnesses comment on IEPs in that regard?

**Vice Chairman:** I take it the Deputy intends to pose his questions one at a time.

**Deputy Pádraig O’Sullivan:** Yes. I might direct that one to Mr. Harris.

**Mr. Adam Harris:** Two key points are really important. People have very different understandings of what the term “IEP” means. An individual education plan is an evidence-based approach to supporting people within school. As the EPSEN Act describes a particular approach to IEPs, it is correct that this approach is not required because it has not been commenced. However, this is not to say that there is no need to provide an appropriate plan. The Teaching Council of Ireland’s professional code of conduct makes it very clear that there is a requirement to differentiate and accommodate all students and the courts have ruled that every child has a right to an appropriate adequate education and that requires differentiation.

That said, it is critical that teachers are given the support they need to understand and better meet the needs of students because we know the vast majority of teachers really want to do that and already do a good job. Critically, what this Act should do when commenced is make sure parents have a right to be involved in how that planning takes place and there is transparency around that planning.

**Deputy Pádraig O’Sullivan:** We had a good news story last week in Cork relating to the

foundation of a new special school in Carrigaline. As a public representative, I found that process exhausting and I can only imagine what parents fighting for a number of years for that right felt. Consequently it is very welcome news. Listening to Senator Dolan, however, it is clear that there are similar issues in other parts of the country. Any public representative will tell you that the vast majority of parents who come to him or her regarding special education provision feel exhausted. The common trend seems to involve fighting against the system. This is in no way meant to be critical of special education needs organisers, SENOs, and the NCSE but it leads me to question their roles. Do they have enough power to do the job they need to do? They are the main point of communication for many parents. Is there any way we can enhance their role, be it legislatively or through the Department? Could Dr. Muldoon answer that question?

**Dr. Niall Muldoon:** From our point of view, there is a sense that SENOs only go so far. They have statutory obligations under the legislation but we need to look at what they are being provided with in terms of the tools and the strength they have when they look for something. In terms of the issue of school places referred to by the Deputy, SENOs should have the strength to sort such issues but we are finding that we are getting involved more and more. In the past year we had two section 37 orders from the Minister. That should not happen. These issues should be capable of being sorted out locally, through the preparation of reports and engaging with school patrons and principals. That should be sufficient, if the statutory backing for SENOs was available to them. That is what we are here for - to look at the statutory obligations that are there, enact what we can and make it as clear as possible what the obligations of schools are in relation to providing for children with disabilities.

**Deputy Pádraig O'Sullivan:** Following on from that, I wish to raise a matter which, since I was elected to national politics 14 months ago, I have failed to understand. We are relying on schools to make decisions to cater for the needs of a certain population that might be in their vicinity. I will put my teacher hat on and suggest that if there is demand in a certain area, then a school should be mandated to address it and cater for it. There are areas in my own county, including in and around Cork city, where there are population centres of around 20,000 people but no autism spectrum disorder, ASD, unit at second level, for example. If we are relying on schools to make local decisions, then the potential exists for deficits in provision in certain areas. Much will depend on how proactive schools are in particular areas. Is there a greater role for the Department in terms of mandating schools? I am aware of the powers available to the Minister, albeit they are used infrequently. Should there be a demand-led model rather than the discretionary model that operates at the moment?

**Ms Lorraine Dempsey:** We have to take a step back and look at why demand is being generated. That involves looking at our whole education system and the inability to meet the needs of children with more complex educational needs. This is where the demand is created, with parents looking for alternative, more specialised school places for their children. We have a pre-existing flaw that has been driving this, year on year. Rather than underpinning the development of an inclusive education, we are moving in the opposite direction. In terms of our obligations under article 24 of the UN Convention and particularly *vis-à-vis* other European countries which have similar but more segregated education systems, the UN committee is very clear that we should avoid promoting segregated education. This means that we must adequately resource mainstream education so that it can be transformed in such a way as to meet the needs of the majority of children, including those with more complex needs. We are creating a demand, year on year, for children to go into special preschool classes and special ASD classes, although special classes are not exclusive to children on the autistic spectrum. We are driving

the demand here by not addressing the fundamental deficits within mainstream schools. That is the starting point for this conversation, notwithstanding the fact that we really need a ten- or 15-year Government strategy, regardless of which political parties are in power, to implement the resource and systems changes that are required to stop that demand from growing further.

We also need a review of special classes and special schools in the context of outcomes. We are looking at inputs and how many special classes we can get open because the demand is there but we are not really looking at the outcome of the development of such classes in the context of children's ongoing educational future. Where do they end up when they go down this road? Do they end up in employment or in day-service provision? What are the outcomes and are they quality outcomes directed towards the needs of the child? I urge the committee to take a step back when looking at this issue.

What we have currently is a lack of future planning in terms of the demand for special educational supports. I refer here to additional special education teaching support, SNA support-----

**Vice Chairman:** I am sorry to interrupt, but we are over time. I want to invite Mr. Harris to respond briefly before we move on. I am conscious that we are all operating under time constraints but there should be an opportunity, when we finish this round, for contributors to speak again. If there is not, any written correspondence in response to questions or observations will be circulated to everyone. I invite Mr. Harris to make a brief comment.

**Mr. Adam Harris:** I will be very brief. I completely echo Ms Dempsey's point. The data is there so one would have to ask why the advance planning is not being done. There are several issues we must consider if we want to create an inclusive system. There seems to be an element of class involved in this issue. It seems that in certain areas of the country, in Dublin and Cork in particular, people are travelling long distances out of their local communities to attend autism classes because there are no classes in their areas. That is very worrying. The other point I would make is that when we set up special classes, the idea was that people would get a lot of support and would, over time, integrate into mainstream. Over 90% of the young people on the autism spectrum starting in a special class are remaining there because families do not have confidence that they will get the support they need in mainstream and that is where there is a huge amount of work to be done around capacity.

**Deputy Donnchadh Ó Laoghaire:** Gabhaím buíochas leis na haíonna go léir as a gcuid ráiteas agus as an bhfianaise atá tugtha dúinn acu.

The AsIAM written submission to the committee refers to the fact that trust between parents and children with special educational needs and the Department has been very severely damaged by the revelations on "RTÉ Investigates" of an adversarial approach and the fact that there is a daily battle for rights and entitlements, school places and so forth. The point is made in the submission that there is an opportunity, with the review of the Education for Persons with Special Educational Needs Act, not just to change the debate but to change the culture. We need to see the Department and the bodies under its aegis move from an attitude of being gatekeepers to being collaborators with the families represented by the organisations here today.

I will pose a number of questions now. Unfortunately, I will not be able to stay until the end of the meeting so I will not be able to come in again. My first question is directed to Dr. Muldoon, but if others also wish to respond, they are welcome to do so. It occurs to me that there is no way this issue is going to be solved by education alone. We can invest as much as

we want in special education teachers, SNAs, special units and so on, which will make a significant difference but if we do not invest in clinicians and in ensuring that there are enough educational psychologists, speech and language therapists and so on, to ensure that children are getting supports in a timely fashion and with the frequency needed, this will all fall down. I ask Dr. Muldoon to comment on that.

My next question is for Mr. Harris. There has been a lot of discussion recently about the so-called New Brunswick or full integration model. It seems to me that balance and discretion are crucial here. People will have differing opinions on this and we must continue to explore the issues involved. It is my view that at this point in time we still need to have special schools for those parents who want them. Some parents will not want that option for their children but a lot will and we must continue to proactively plan for that demand.

Deputy Pádraig O'Sullivan asked an important question of Dr. Muldoon earlier and I ask the representatives of Inclusion Ireland to respond on whether we are getting the most out of our SENOs and the NCSE. How can we ensure that under a new or revised Education for Persons with Special Educational Needs Act they play the most constructive role possible?

Finally, to the representatives of Down Syndrome Ireland, there has been a lot of discussion, rightly, about expanding the summer programme to all of those with Down's syndrome. That is essential and a lot must be done in that regard. We need to be looking at September and the next school year to ensure there are adequate supports on an ongoing basis. We are not going to make up all that lost ground by the start of the new school year. Accordingly, we need to invest on a longer term basis as well.

I thank everyone for attending and responding.

**Dr. Niall Muldoon:** There is no doubt that we have always believed children's rights needs to be a cross-governmental enterprise. It must involve the Department Children, Equality, Disability, Integration and Youth, as well as the Department of Education and the Department of Health. Even a simple point such as school nurses should have been sorted out years ago. In that case, there was joint funding between the Department of Health, the HSE and the Department of Education to provide services to children who need school nurses.

It needs to be done on a consistent basis. Legislation needs to start moving to force Departments to go past their old ways of doing things. As has been said, there is a series of battles for parents all the time. If Departments are fighting among themselves as to who provides what service, parents get caught up in that too.

We need to create multidisciplinary teams. We have a special inclusion model coming through which will involve therapists with the teaching education system. We also will have psychologists providing more assessments. The Education for Persons with Special Educational Needs Act 2004 and its review allows a move to a collaborative approach rather than gatekeeping and fighting. That is the way forward as that will save money in the long run, if Departments are willing to do that. Legislators and committees like this need to push the Government in that direction.

**Ms Nicola Hart:** I agree with the Deputy that we do need to consider additional supports, particularly over the summer and in September when children start school. I realise we are looking long term here and this is the short-term piece. However, failing to do that will mean school placements will break down. Then we will be putting even more pressure on special

education systems, as well as families, who are already stretched to breaking point. Additional consideration needs to be given to that this year, particularly by the Department.

**Deputy Aodhán Ó Ríordáin:** I confirm I am in Leinster House.

We always learn more from these interactions which makes them so worthwhile. Even concerning some of the language used, I have learned so much from the contributors with whom I have had interactions in the past. The kind of language used, such as the “D” in ASD unit standing for disorder, needs to be challenged. We speak about training for teachers. It is not just about teachers but entire school communities. Society needs to up its game in order to have a fully functioning Republic which actually treats everybody with the proper level of dignity in the space in which they interact with the State.

I am concerned about us having the same debate in 20 years’ time, over and back. Is there something fundamentally wrong with the education system that it needs a constitutional referendum? We have created a system which is not a State system, but a State-funded system. It places all the power with patron bodies and boards of management with which a Minister could only interact recently. Fundamentally, that is where the power is. We are always going to be just tinkering with it unless we fundamentally overhaul the ethic and belief system around the education system.

We cannot take a foreign model of special education and introduce it in Ireland because it will not fit. It is designed not to fit. People running around the place and trying to go outside their communities in order to go to school and chasing down resources is madness. Other jurisdictions, in particular the Nordic countries, would think it was crazy that people could not just access these services as a right in a State-funded school system. We do not have a State system. We have a State-funded system.

A fantastic opportunity is being afforded to the Government in terms of a constitutional convention-citizens’ assembly on education. Are these the big questions we need to start asking? It should not just be questions about money here or there, or a unit here or there, or a change in legislation here or there. Are we going to have this row in perpetuity unless we radically overhaul what the education system does and what it is there for? The child is not at the centre of the education system. It is between what the patron body wants, what a teachers’ union wants, what a political party wants and what a programme for Government says. Rarely is the child at the centre of this discussion.

**Vice Chairman:** Does Deputy Ó Ríordáin want to direct this to a particular witness?

**Deputy Aodhán Ó Ríordáin:** Anyone who wants to dodge it should be allowed to dodge it. Anyone who wants to take it should be allowed to take it.

**Ms Lorraine Dempsey:** I am quite concerned about having that sort of public convention on the future of education, given the context that every five years or so the National Disability Authority does a survey on public attitudes to disability. The first time I read the survey was in 2011. I was shocked then that 24% of the population who were surveyed felt that a child with autism or intellectual disability should not be educated in a mainstream class with their children.

The last survey was done in 2017 and one would have thought we would have moved on from that. However, the same question was asked and 28% of people surveyed said they did not want a child to be educated in a mainstream class if he or she had autism or intellectual disabili-

ties. This is our ground zero in terms of public attitudes. Having a discussion in that context is really challenging, although I get what the Deputy means in terms of where the bedrock needs to be constitutionally.

Notwithstanding the Constitution, we have an obligation under the UN convention, which is expressed in Article 24. That, for the Government in all its policies, should be the foundation of where we start, where we need to go and what the Government needs to comply with, given that it is drafting those reports currently. The State has an obligation to comply with the UN convention from the get-go, regardless of what our Constitution states.

**Deputy Aodhán Ó Ríordáin:** I saw Dr. Muldoon indicate and I would be interested to hear his perspective.

**Vice Chairman:** Mr. Harris will come in next and then Dr. Muldoon.

**Mr. Adam Harris:** It is a great question. One of the problems we see in our day-to-day work, although the Ombudsman might be better placed to comment on this than anyone else, is that there seems to be a total deficit of responsibility built into our education system where the Department blames another group or another group blames the Department. The only stakeholder who does not seem to have a central voice or a relevance is the child.

One of the things that really worries me, and we see it every day in our work, is that often children must experience egregious breaches of their rights within the education system before they can be reconciled. Sometimes an issue arises and it is brought to the attention of the Department but it will not touch it. As a result, people are left for more than a year on their educational journey with a clear breach of their rights because of the current system, which does not favour the child.

We very much need reform but legislation only ever gets so far. The big word I would use here is “confidence”. We will not be able to create an inclusive system until parents and families have confidence in it. That has been blocked by two issues. First, there was a promise around the Education for Persons with Special Educational Needs Act 2004 which was not delivered on. Second, most recently during the Covid-19 pandemic, families were sent a clear message that if they chose to send their children to mainstream school, their rights would not be guaranteed in the same way those rights would be guaranteed for those in special schools and classes when it came to reopening. That is not without consequence.

**Dr. Niall Muldoon:** On the education system, if we could start again, we certainly would. The system is old and antiquated. It was built around a charitable system whereby the religious provided the services and we were grateful for it. When I talk my colleagues in Europe, they laugh at the concept that the Department of Education does not have control of schools in the way it should. I wrote to the UN Committee on the Rights of the Child in 2015 looking for a recalibration, as I call it, where the Department must have oversight of those sorts of schools at a much more local level so it can take control, forward plan and be held accountable. This allows about four different steps for disassociation of responsibility. That is wrong. Again, that is where we need to go.

I do not think we need to look at a constitutional referendum. There is a constitutional right under Article 42.4, which allows the right to education for our children. We need to just follow through on that in a child-centred manner. The education system is for our children, not our schools, patrons or the Department of Education. It is for our children. We need to put them at

the heart of it, listen to them and make sure that they all have the system they deserve. That is the crucial way forward.

**Deputy Carol Nolan:** I apologise for having to step out for a few minutes. It is a busy enough day. I thank all the witnesses for their presentations. As somebody who comes from an educational background and has taught special needs children, I completely understand what is going on here. It is unacceptable that parents have to fight tooth and nail. I have also seen cases where teachers have to fight tooth and nail for IT equipment and basic things children need to support their learning, as well as trying to get them assessed and get access to therapies. I have first-hand experience in that regard.

The lack of responsibility and so forth in the system has been referenced and, certainly, that is a major issue. How do we overcome the lack of accountability? We need to have the same robust approach I see in other areas, such as climate action, where there are targets in place and consequences for missing them. We are dealing with children who need to be given every chance to reach their full potential as is laid out in the Education Act 1998. At this point, there needs to be more robust measures and more robust accountability in place because we have fantastic initiatives.

I wholeheartedly welcome many of the initiatives in the EPSEN Act to create a more inclusive society and a more inclusive education system for all children of different abilities. I do not use the word “disability”, rather, I use the term “different ability”. We need to wake up to the sense that something needs to be done fast. This has dragged on and on. It often struck me, as a teacher with a master’s in special education, which I loved doing, that it makes no sense that IEPs were never made mandatory. It was considered good practice, whereas the classroom planning is mandatory. Every teacher, when qualified, has to draw up his or her fortnightly and monthly plans, policy objectives and what not, at a whole-school level. Questions need to be asked here. Why is it not on the same level? We are talking about inclusiveness and equality but, certainly, there are serious gaps in our education system that need to be addressed. I ask the witnesses to indicate how we can make things more accountable in our education system? How we can place more of an onus on Government to deliver on these targets and great initiatives?

I am sure the officials will agree it is imperative that there is early intervention when a child is diagnosed with autism. There are reports of considerable delays in the provision of support services to children diagnosed with autism by NEPS. Indeed, it is very much a postcode lottery. The standard and quality of service depends on where one lives, which is completely unacceptable. Can NEPS specify the waiting time from when a child gets a diagnosis of autism to the provision of therapeutic services, outside of those provided in school? Can it provide information on that? Is there a specified target date for providing these services after diagnosis? Is it the case that while some measures have been consolidated into law, the actual implementation is just not there? Certainly, that is what we see. I would like to hear the witnesses’ thoughts on that.

I want to acknowledge that I met Gavin from AsIAM. We had a good meeting and discussed many of the issues. I am more than willing to support the witnesses in the context of many of the concerns they have had for far too long. There needs to be more collaboration among all stakeholders. There needs to be co-ordination, certainly among therapists and schools. We should have on-site therapists in our schools and more collaboration. That is just not there. The access to therapies is very much a postcode lottery. I dealt with a newly married couple who felt that if they moved to a certain county, their child would get better service. That is not acceptable. It is not good enough that people have to go to that extreme.

**Vice Chairman:** There is only one minute and 15 seconds left for a response.

**Ms Lorraine Dempsey:** Regarding legislation and accountability, because there has not been full implementation of the EPSEN Act, we have skirted around it with other legislation. Many of my colleagues on the committee were party to discussions around the Education (Admission to Schools) Bill and the student and parent charter, and the impact they would have on ministerial accountability for allocation of school places for individual children. Somebody asked about the SENOs earlier. We need people with teeth who can advocate for our children and not wholly act as gatekeepers. That is the way parents currently see them.

On Deputy Nolan's point in respect of the postcode lottery, there are national programmes to develop children's disability network teams where access to services is delivered regardless of the school setting or where the child is living. One can move from any school setting or any county and the model of service delivery and access to those services should be the same, albeit with challenges around resources. That will get rid of the postcode lottery we have currently.

In the context of children having an assessment that leads to a diagnosis - the Deputy referred to children on the autism spectrum - they do not have a statutory right to intervention. It stops at the assessment. The statement a child gets will state when and where those interventions should be delivered. However, we have seen reports which state that these interventions will be delivered in 56 months because while there is a statutory requirement to put the actual date on the statement, there is no requirement to deliver. Again, people must have a statutory right to the delivery of interventions that will actually lead to positive outcomes for children, because it is not about whether somebody gets a block of six speech and language therapy sessions, it is about the outcome we are seeking to achieve. That is what we all need to move towards because we are very focused on inputs but not what it means for the child in long-term outcomes.

In terms of accountability, I go back to Deputy Ó Ríordáin and how he set out the relationship between the Minister, the Government, schools and boards of management which puts children as piggy in the middle. I have stated before that we can complain to our local schools, go through complaints processes and we hit an impasse when it gets to board level. The SENOs do not have teeth to take any action, the schools say there are not adequate resources, the SENOs say there are and the child ends up outside of school. We continue this, year after year. All the Deputies and Senators have had public representations from their constituents which portray the vicious cycle in the middle of which children constantly find themselves, without a school place that can actually meet their needs.

**Vice Chairman:** It is such a difficult situation for so many. I thank Ms Dempsey. I ask Mr. Harris to make a brief comment.

**Mr. Adam Harris:** Building on that, if we are serious about the UN convention and statutory rights, and also holding the Government to account; if the Government is serious about the convention it should ratify the optional protocol. That would then mean if people breached rights, they could be held to account through the UN committee.

**Senator Pauline O'Reilly:** I could not click the button in time to get the slot before Deputy Nolan. I have been listening in and have read all the statements. I thank everyone very much for that. I have also attended the Joint Committee on Key Issues affecting the Traveller Community and education and educational attainment is right up there. This is not just an equality issue. It is about equity and the fact that some people need more in order to achieve what they

can for society. They include all of the people the witnesses represent.

I previously tabled a Commencement matter for AsIAm and I have met many of the staff in the organisation, specifically on the issue of individual educational plans. It is of huge concern to me that 17 years after it was passed, many of the elements of the EPSEN Act 2004 have not been commenced. In the US and UK, these processes are statutory. We can say that most schools do them but as a lawyer, I know that is not really the point. The point is that one must have confidence in the system.

On Deputy Ó Ríordáin's point, nothing in the Constitution lays down the patronage system. It is more a matter of how we as a society organise our educational system. Many will know that I am most passionate about having a citizens' assembly. The point about surveys is one issue. I take on board that when a survey is completed, it can be disheartening to see people's reaction. However, it is about moving the conversation and the dial around how people engage and think about those with disabilities. It is key that we have those conversations to move that dial. What are the witnesses' views on that?

The establishment of a citizens' assembly on education is part of the programme for Government. I believe all of the organisations represented could and should feed into that and try to progress and promote it sooner rather than later. That said, there is a lot of low-hanging fruit, for want of a better term, that can and must be progressed anyway. People have human rights, regardless of whether we have these conversations. We do not need to have the conversations to know that people have human rights.

I agree that rather than saying we would like to do certain things, there is no good reason not to take steps to ensure that people who go before the courts are able to point to a law that sets out their right, assert that it has been commenced and ask the Department to ensure they receive everything to which they are entitled under that law. I am a former chair of Home Education Network Ireland. I sometimes make the important point that half of those who were home educated chose to do so, while the other half were home educated because they were let down by the education system. There are higher levels of those with disabilities in the home education network than in the general population. That says that we are letting people down.

I think we would all agree with the witnesses' opening statements. It is hard to ask questions that have already been answered. However, I would like to hear their thoughts on the issue of a citizens' assembly. I also note that the establishment of such an assembly does not mean we should not deliver on the other obligations outlined by the witnesses.

**Mr. Adam Harris:** I totally agree with the Senator. Not only is a citizens' assembly an opportunity in a constitutional context, but there is also a huge opportunity in the context of Covid-19. Many assumptions were made about how schools and society as a whole should work. There is an opportunity for us to call these assumptions into question. Many children were not having a positive experience in school prior to Covid-19. There is a chance for us to ask now why that was the case and how we can make it better. There is definitely a moment and a need to create the space to have that conversation.

**Ms Nicola Hart:** The Senator mentioned the percentages to which Ms Dempsey referred. Those percentages are unlikely to change because what we are seeing at the moment is children who are not getting the resources and supports they need to function effectively in an inclusive education. Perhaps people are not so much objecting to the idea of having inclusive education or a child with a disability in the classroom, as to having a child who has not been well sup-

ported to succeed in that classroom. That needs to change, along with the attitude. The attitude change will come if that change is made.

**Ms Lorraine Dempsey:** The Senator raised the issue of having a statutory right and international systems. If we look across the Irish Sea to our neighbours, we see that they have a much more robust statutory legal framework for children with special educational needs. However, while there is a framework in place in the UK, where funding is inadequate, it leads parents to tribunals. We do not have a statutory appeal system under the EPSEN Act 2004. That is one of the elements that was not implemented. However, if we bring in an appeals system under a statutory framework, we do not want to end up shepherding families down that road because we simply have not provided for their children in an adequate way. That is the case in the UK, particularly during the Covid pandemic. The funding mechanisms in the UK are through local authorities which have care and education plans. It is an integrated plan rather than a singular education plan. Where the local authorities have made funding cuts, it has often impacted on children with special educational needs there. We do not need to set up a system that becomes adversarial. There are children going to the High Court and their parents are taking cases. We need a system that does not push people through that route because of the lack of resources.

I agree with Ms Hart on why the attitudes of the public are so poor. I hear parents screaming for supports for their children every other day and detailing their bad experiences.

I apologise on behalf of Ms Turley, who has gone back to work, but I wish to speak on her behalf about something she expressed about her lived experience. Ms Turley started in mainstream school and her mother lost confidence in the ability of the school to provide for her needs. Her parent made the decision that she needed to go to a special school. At that young age, it was not Ms Turley's choice or preference. She did not want to be hidden. The following are her own words:

I did not want to be hidden or different. I wanted to interact with others. I wanted to be with people who were going to bring me on.

That has had a long-standing effect on Ms Turley, who ultimately ended up on the Trinity access programme and is in part-time employment. However, her journey through was like that because the right supports were not developed for her school to deliver for her, and her parent the difficult decision to move her. It was not necessarily in the best interests of the child, society or the children in her class.

Ms Dempsey mentioned that inclusion starts with education and inclusive communities. If children are not educated alongside other children with disabilities, they do not get to see them. When children with disabilities grow up into adults with disabilities, sometimes those adults are further segregated and are in services based outside of towns. They are not seen, heard or part of the community. If we are going to pay this forward so that we can improve employment prospects for people with disabilities, it starts here. It starts before they ever get to primary school. In fact, it starts at preschool. That will shift our attitudes further in ten or 15 years' time because they will be the people we grew up with next door who continued their educational pathway alongside us, into employment and so forth.

**Deputy Rose Conway-Walsh:** I thank all the contributors. I am a long-time admirer of all of the work done by AsIAM, Down Syndrome Ireland, Inclusion Ireland and the Ombudsman for Children's office. I have a particular interest in autism.

A child who was born when the EPSEN Act came into force will be 17 years of age now. My God, that is an absolute disgrace. That really speaks for itself and to the fact that we have an enormous problem. Will we be dealing with the same situation 17 years from today? That is what we face as a committee.

It is very clear that there is an enormous implementation deficit. I understood Mr. Harris when he spoke of the need for us to conduct a legislative review and implement a human rights roadmap.

Ms Dempsey mentioned education. Inclusion starts with the education and in That the legislation must go hand in hand with the cultural change was mentioned also. That is not a major request and it should not be something that should be added on to this.

I have a number of questions. First, I ask all the representatives why they think the EPSEN Act has not been implemented and why did it take 12 years for an autistic person to be on the National Council for Special Education? We must examine the why in all of these things to see where the blocks and the barriers are. I also wish to ask about the interface between Departments because that is where the biggest issues I have come across are. Who, therefore, is accountable and who has overall responsibility? Who is going to ensure the Departments and the different areas of responsibility come together to put the child and the family at the centre of what is being done? Obviously we all welcome that €2 billion has been allocated. There are 1,423 new staff for educational needs this year. My fear is that Government after Government is almost throwing money at this. How are we measuring the outcomes there? How are we ensuring the money goes to the right place? In the case of a lot of these issues, there is a whole industry set up around them without ever involving the people directly affected. While I believe there is talk of €5 million being spent in recent years on legal cases, that is the tiniest tip of the iceberg. Most families cannot do that because first of all, they are in fear, and we must remember that. Many families and people who are directly impacted are in fear of losing what they already have and most families cannot afford to take on the might of the State financially as well.

I have a specific question for Dr. Muldoon. I refer to families or individuals who want to find out information held on them by various Departments, whether there is a legal case or not. Does, say, an autistic person have a right to get his or her file without it being redacted? I have several other questions but I want to hear from the witnesses.

**Vice Chairman:** Will Dr. Muldoon come in on that?

**Dr. Niall Muldoon:** On the Deputy's question about the files, I would not be 100% sure about it. It would be a matter for the Data Protection Commission. Again, if one is putting the child at the centre of one's thinking, then one would expect he or she should be able to get an unredacted file on himself or herself without it interfering with the rights of other people. That is where the caveat comes in and redaction happens. Certainly, what we have seen so far from looking at "Prime Time" - and the Deputy mentioned the culture - is that if we are going to create confidence and security for the families, then the culture we have seen so far and which was highlighted by the whistleblower was far from what we want with regard to collaboration and co-operation.

To answer the Deputy's other question about the interface between Departments and overall responsibility, we had a great success with an investigation we did with Jack, a little boy with severe disabilities who had a brain injury and was kept in hospital for two and a half years in-

stead of being brought back to his own home. Tusla and the HSE argued over it. We now have a situation where they have found a way to work together and to share the funding for children like Jack. They have done the same in the case of another child, Molly, where they are sharing a budget. That is the first time I have seen it happen that there is a legislative underpinning within the budget and the Votes to allow a certain cohort of children, who are being cared for by two different Departments, to be funded by the two Departments together and that they have got a process in place for that. Making that happen was driven by the CEOs of both the HSE and Tusla and the Departments which fixed it. We need to get to a situation where the Department of Health can share some of its money with the Department of Education. Again, this is forward planning. In the case of children with severe and profound disabilities in particular, you know who they are from the day they are born, unless it is a brain injury, and again in that case, you can predict very quickly what they are going to need in the future.

We had a meeting last week with the Department of Children, Equality, Disability, Integration and Youth. It was talking about legislating for mandatory collaboration and co-operation across Departments. It is terrible that we have to do that but if that is the way forward, let us do that. Let us mandate that Departments must co-operate and collaborate on behalf of the children. Again, the child then becomes the centre of decision-making and it takes away those barriers so we can share information, share budgets and predict what is needed. That way, nobody needs to fight over what is required because going back to what Mr. Harris said at the start about constant battles with families, we do not need to have them if we predict, as much as we can.

**Vice Chairman:** I am aware the Deputy had other questions but we are out of time now. If we have a second round I will allow her in then.

**Deputy Jim O’Callaghan:** I thank our guests for their attendance; I have found it very helpful. At the outset, it must be said that when the Oireachtas enacts legislation, there is an expectation that such legislation will be commenced relatively soon after its enactment. It is unusual and, to be frank, embarrassing that nearly 50% of the sections of the EPSEN Act, which were enacted 14 years ago have not yet been commenced. In light of the fact that our witnesses are aware that a review of the EPSEN Act is to take place, do they want the outstanding sections within the Act to be commenced or do they want the review to take place? What is the priority and the advice that they have for us, as legislators, in respect of that choice? I do not know whether Ms Hart or Ms Dempsey wants to come in first on that.

**Ms Lorraine Dempsey:** On the question of review versus enact, at this stage, 17 years later, we would be required to review the sections that have not been enacted. There has been a considerable amount of policy development around the area and policy recommendations from the NCSE that are themselves sitting on shelves and have not been taken up by the Department of Education under each successive Minister. I therefore think we need a wholesale review of where we have come to over the last 17 years in terms of policy and implementation and then look back to see where are the divisions between the enacted parts of the legislation around the IEP, because a lot has changed since then. Our education system has changed since then, as have the structures of the HSE. Therefore a review would be the starting point rather than enacting something which may, 17 years later, be flawed in itself.

Notwithstanding that the Deputy mentioned that it was unusual for legislation to not be enacted, I was before the Joint Committee on Disability Matters this morning and can tell him that it is not unusual at all. There is the Disability Act 2005 and there is the Assisted Decision-Making (Capacity) Act 2015, which is not fully implemented and hopefully next year we will have the decision support service. Several items of legislation that directly impact people with

disabilities, both children and adults, are not fully enacted. Our Government and our Oireachtas, our legislators, have form on this unfortunately and the EPSEN Act is not an isolated scenario at all. For people with disabilities, it feels indicative of our status in society that we do not have that legislation to support us and our children. It is not unusual.

Dr. Muldoon referred to the Disability Act. You must look at the EPSEN Act and Disability Act in parallel and what both were setting out to achieve with the different types of assessment and outcomes. Thus, it should be review first.

The question as to why the EPSEN Act has not been implemented was mentioned. I think it was a previous Minister for Education who indicated, around 2012 or 2013, that it would cost three quarters of a billion euro to fully implement the Act. Over those years, Inclusion Ireland has asked for a breakdown of costs of bringing in IEPs, the required training around them and the costs associated with delivering them, in order to let us see what it would look like in segments and for the Government to look at the full implementation.

**Deputy Jim O’Callaghan:** Okay.

**Ms Lorraine Dempsey:** We ourselves would be asking how much this would cost in its current form. The question of whether this is actually where we need to go would be for the review. There would need to be costing of the review and then a plan for implementation.

**Deputy Jim O’Callaghan:** Does Ms Hart want to come in there as well?

**Ms Nicola Hart:** I fully agree with what Ms Dempsey is saying on the need for a review. However, my fear is an extended review with no timelines is just going to kick the can down the road for another decade so we need to be very careful how that is framed.

**Deputy Jim O’Callaghan:** If I can, I have another question for both Mr. Harris and Dr. Muldoon in respect of the opening of ASD classrooms. In my constituency, Dublin Bay South, there is a severe shortage of ASD classrooms in primary schools. I note Mr. Harris indicated it is perhaps as a result of class or issues such as that, but it may be more complicated than that. I know from my experience in the area that when a primary school eventually makes a decision to provide ASD classrooms it can have a very positive and transformative effect upon the school in general. What advice would Ms Harris or Dr. Muldoon give to schools that may be hesitant about opening ADS classrooms? Obviously, it is not simply a personal choice for them but what can be done to encourage them to go along with the opening of such classrooms?

**Mr. Adam Harris:** Can I respond to that question?

**Deputy Jim O’Callaghan:** Yes.

**Mr. Adam Harris:** We need to move beyond the hesitancy because it does not have a role in the discussion. Even during the recent 37A process that looked at south Dublin, it was noted in the responses of some schools that they had to expand because the population grew. In other words, it was a recognition that sometimes they had to expand beyond their means to meet the needs of the children in the locality. I do not think they are exempt from that obligation if some children happen to be autistic. There are concrete things we can do. One is that a process such as the 37A process needs to take place much earlier in the year in order that people have time to plan. There needs to be much better co-ordination between the building section of the Department and the sanctioning of an autism class in order that the school can get the supports and set it up to succeed. Involve Autism in the Deputy’s locality is doing great work on this. There are

not more autistic people in one part of Dublin versus another. There is a very clear correlation. This comes back to the question Deputy Ó Ríordáin asked, that is, why we do have an education system? It must be about equality of opportunity and every child having the best chance. We cannot allow academic prestige or tradition to supersede that.

**Deputy Jim O’Callaghan:** Does Dr. Muldoon want to add to that?

**Dr. Niall Muldoon:** Yes. I agree we need to get past the hesitancy. It should not be a choice. It should be included in plans and planned well in advance. All those parents knew what they needed from their schools years in advance and that system is in place. At last week’s meeting of the committee a representative of the Department’s building unit spoke about having a very fluid situation to identify these places. I find that incomprehensible. It is not fluid. These children are there. They have been fighting for these places for a long time. We should know what we need and put it in place.

The Minister of State, Deputy Madigan, is talking about setting up a five-year projection plan for the National Council for Special Education, NCSE, as to how we get these places and what places are needed, but we should have that well planned by now. It is a ludicrous scenario. It is a way of coping out. We talked about the legislation and a review earlier. There is a Minister with responsibility for special education and inclusion and a Minister with responsibility for disability in the Department of children. Those two people need to lead the way and make sure they work together as a co-operative to get both the Disability Act and the Education for Persons with Special Educational Needs Act working to the best advantage of the children. That will take away all the hesitation, all the grey areas and provide resources to all those schools. As the Deputy said, I found every school I have been to where there have been special education children and special education classes has been nothing but enhanced by that. We need to get to where the running of schools and such classes should never be in doubt.

**Deputy Jim O’Callaghan:** I concur that hesitancy should not come into it. In fact, there needs to be a recognition that providing ASD classrooms should be as fundamental as providing junior infants, and schools need to recognise that. I thank the Vice Chairman.

**Vice Chairman:** I will move on to Deputy Farrell.

**Deputy Alan Farrell:** I thank the Vice Chairman. I confirm I am in Leinster House. I thank all the witnesses for their contributions for the last hour or so. It has been illuminating. I have a question for Dr. Muldoon and a statement to which I invite contributions. In an ideal scenario we would not have elements of the Education for Persons with Special Educational Needs Act that have not been commenced or a budgetary deficit in the provision of services, and Dr. Muldoon touched on this and that prompted my question. The resolution to the hesitancy is not only an issue of planning but an issue of the deficit in responsibility, to which Mr. Harris referred, in terms of the schools and the fact that schools are not centrally managed by the Department of Education, by the State. Is part of the solution to all the issues we have discussed for the last hour the taking over of schools, not in a pejorative sense, by the State?

**Vice Chairman:** Does Dr. Muldoon want to respond to that question?

**Dr. Niall Muldoon:** “Taking over” is probably the strongest possible term to use. The term I would use, which is cited in the UN Committee on the Rights of the Child, is “recalibration”. The Department of Education must have more say and input on where there should be less autonomy in circumstances where we are talking about the rights of a child to proper education,

that is, specialised education. There should be no doubt over that. Again, the only question should be how a school gets the resources to provide it, not whether it will provide it. It should make sure the resources come on stream. For example, if five places are needed next year, the school needs to provide those places. Ultimately, a school will know it needs those five places three years in advance and the funding for them will be put in place. There should be no equivocation about that. I would call it a recalibration but there should be a more hands-on input at Department level which in turn will place more responsibility on the Minister.

**Deputy Alan Farrell:** I thank Dr. Muldoon for that response. I understand his position. I used that term for want of a better expression, but his term is superior.

My experience of some of the schools in my constituency, and I am sure this is echoed by my colleagues who are members of all parties and none, is that some schools, teachers and coordinators go above and beyond and they are an extraordinary credit to their professions. However, given what has been said today, at previous committees in discussions with the advocacy groups represented today and others, it is clear that implementation and the point Ms Lorraine Dempsey made in response to the question as to how much this would cost in terms of the implementation of individual education plans needs to be answered promptly. If we consider the 2006 or 2008 projected cost of fully implementing the Education for Persons with Special Education Needs Act at that time was €230 million a year and the figures now emanating from the Department of Education of €2 billion, or more than 40% of the budget, invested per annum in special education, with the best will in the world it is simply not enough. All the other questions I was going to ask have already been asked.

I said I would make a remark to which I would invite a response from the remaining witnesses or, indeed, from Dr. Muldoon. It is related to the question of patronage. With the deficit of responsibility to which Mr. Harris referred and the adversarial system that exists with parents having to fight for the rights of or for services for their children, do the witnesses as a group believe the Department of Education is either equipped or forthright enough to foresee the requirements in any given school community in terms of the provision of supports for children with additional educational needs and the overarching desire and requirement, which I believe is shared by the witnesses, that an integrated education is provided to as many pupils as is possible throughout their education? I note Ms Lorraine Dempsey is indicating she would like to respond.

**Ms Lorraine Dempsey:** With the permission of the Chair, I will respond. We would not have confidence that is possible right now. If we consider some of the systems the Department of Education has brought in to try to meet the needs of children with special educational needs in mainstream settings, that is, the special educational teacher allocation model and the upcoming special needs assistant, SNA, allocation model which will be based on the same data the Department will be collating on schools, there are already issues with the special educational teaching allocation model. Both Mr. Adam Harris and myself sat on a working group which designed the school inclusion model and the proposed components of that, of which only one was the SNA allocation model that the Department wants to roll out. We took that work as a wholesale piece of scaffolding supports around a school. That was the psychological support, nursing supports which Dr. Muldoon mentioned and providing an accurate level of special education teachers to support children in mainstream settings. Currently, schools and patron bodies are raising issues, particularly around developing schools that year on year, have additional classes coming in but do not have children leaving. They are growing schools yet they are now expected to deliver special educational teaching supports, and potentially SNA supports, on the

basis of data they submitted a couple of years ago when they did not have the additional pupils in the school. Without rectifying the current issues around how the Department allocates resources to schools, we are very concerned that it would be able to plan accurately for the needs of children as we move forward.

**Deputy Alan Farrell:** I thank Ms Dempsey. Does Mr. Harris wish to comment?

**Mr. Adam Harris:** First, two positive things that have been announced are that no new schools should be built without special classes. That is a useful planning mechanism. I know the Minister of State, Deputy Madigan, has indicated a desire to limit the choice around provision to make it a much more defined process. That is important.

When we talk about data, we have to recognise at the moment that the approach by the Department and the NCSE often seems to be getting parents to go around with a clipboard and to demonstrate demand, which is bizarre. It is certainly not the level of sophistication one would expect when we know what the prevalence is, for example, of a variety of disabilities within the community. There is a need to use the available data in a much better and more comprehensive way. I would, however, echo what Ms Dempsey said in terms of the data that we are using at the moment. I have substantial concerns, particularly around the special education teaching model that is being proposed to use for the SNA model and which has not been the subject of consultations in the way a commitment was given it would be.

**Deputy Alan Farrell:** I thank Mr. Harris. For the purposes of the committee, it is important to characterise the requirement for special educational units within new schools to be extended substantially. A huge number of schools are being substantially extended and they are not currently subject to that provision. I believe they should be. I have come across it a few times in my constituency, which is one of the fastest growing in the country, beside Dublin West. I certainly take on board Mr Harris's point, however. Do Ms Hart or Dr. Muldoon have any remarks on my comments?

**Ms Nicola Hart:** I can come in if that is okay. Down Syndrome Ireland still finds it baffling that, as a general rule, our children are diagnosed at or before birth but although the education system has six years to prepare for them to come, it still seems blindsided by it. It has no idea how many children with Down's syndrome are currently in the education system. There is, therefore, obviously some huge deficit in planning.

As well as the issues between the Department and schools, the joint planning that is needed between the Departments of Education and Health really does not happen in the way it should. I remember an individual case where the HSE and the Department of Education were arguing for a year about whether a laptop for a child should be provided through education or health funding. These kinds of things should not be happening.

**Deputy Alan Farrell:** No; they should not.

**Dr. Niall Muldoon:** I do not have anything extra to add except that the concept is not beyond us. Yesterday, we were looking at helicopters flying on Mars. We should be able to know how many children are coming into our schools. A first-year mathematics student or computer programmer could set that database up in no time.

**Vice Chairman:** We have moved swiftly through all the members. I have the opportunity to say a few words as Vice Chair. I will then allow members to come back in. Deputy Conway-Walsh indicated that she had more questions. We will, therefore, have a few minutes to come

back.

I thank all the witnesses. I found it illuminating and frustrating at the same time, in coming back to this issue that is so fundamentally important to our society and the way we operate, to see the blockages that continue to be an issue. We absolutely must do our best in terms of ensuring that every young person with an intellectual disability has the opportunity to have an education plan that is suited to them. It is going to take us a long time to get to that point.

I have a number of general questions on the particular topic we are discussing for whosoever of the witnesses wishes to respond to them. It is good that the Minister stated that one of her priorities is to review and update the EPSEN Act, which as we know is 17 years old. Do the witnesses have any views on what specific areas of the Act need to be renewed or amended?

Second, we heard from Deputy Pádraig O'Sullivan earlier that an individual education plan, IEP, was used at his school, which was great. The fact that the Association of Secondary Teachers Ireland, ASTI, and the Teachers Union of Ireland, TUI, have advised their members not to implement individual education plans, given their lack of statutory footing, is absolutely concerning. Could the witnesses comment on their views of the importance of the IEPs? I get a sense they feel it is important but perhaps they feel the lack of statutory footing has had an impact.

Parents are having considerable difficulty in finding a suitable school place, particularly at secondary level. I certainly have found that to be the case for special needs students in County Kildare. Notwithstanding that extra powers were given to the Minister of the day with regard to schools admission, do witnesses think the Department should have more powers to compel schools? I tend to agree with an earlier comment that we need to incentivise schools, as opposed to compel them, or perhaps take the fear some schools may have regarding providing education for those with special needs. Perhaps the witnesses could comment on that.

We have spoken about the SENOs, with whom my own experience has been less than satisfactory. In a case with which I had dealings, the SENO's response was to tell parents they could take a section 29 action and more or less encouraged them to do so. That set up a whole adversarial session straight away between the school and the parents and it was not helpful. From what I found, although I have no doubt there are exceptions to the rule, providing a list of schools and telling parents to contact them is not good enough.

My final question is regarding our committee. We will be examining the issue of leaving certificate reform later in the year. As they are here, do the witnesses have any comments on the specific needs of special needs students, particularly around the whole leaving certificate applied? I will take answers in the order of whoever puts their hand up.

**Mr. Adam Harris:** I addressed earlier some of my thoughts around the need for amendments to the EPSEN Act so I will skip over that question.

We really need to change the narrative around the whole area of IEPs. An IEP is fundamentally about taking the adversarial piece out of the conversation and making it a partnership model where everyone sits around one table and asks how they are working in the same direction.

Speaking from my own educational experience, the reason it was positive was that my parents were lucky enough to always meet teachers who were willing to co-operate and work as a team. We need to get that sense of team back. IEPs in the context of the EPSEN Act are one discussion but it has to be very clear that there is an obligation. It is established clearly in a

whole range of circulars, existing policy and court judgments that an appropriate and adequate education must be provided. That requires differentiation and demonstration of how it has been done.

The whole area of SENOs touches on the fact that we keep talking about how EPSEN and disability interact with each other. Certainly, the experience our families tend to have is the word they become most used to is “No”. The moment you get a diagnosis, everyone tells you what they cannot do for you and why you should not talk to them. Nobody seems take the role of saying who you should talk to, however, or if you like, holds your hand and actually guides you along the process. Whether it is enhancing the role of a SENO, changing our approach to the role of a SENO or having a different role that covers all of the agencies, we need families to have a key worker who is on their side and is trying to help them, as opposed to quoting legislation or giving them lists, which really is not very helpful for somebody who does not know the system.

In terms of powers to compel schools, we need to be a lot more defined regarding what constitutes a reasonable excuse in the section 37A process. Some of the responses I have seen include a school stating it is absolutely essential that children have access to a library so it cannot be given up for a class. Libraries are nice to have but the right to an education is a constitutional right and some of our children are being deprived of it. We need to be an awful lot clearer on this.

No school should be able to opt not to deliver the leaving certificate applied. The biggest problem is we have moved children into our education system but we have not changed our definition of success. Many of the problems we are speaking about today come from our definition of success and what is a good educational outcome because we have a system which rewards people who get 625 points but which does not celebrate that for another person, working part-time, living independently and being part of the community is as big and as important an achievement.

**Ms Nicola Hart:** I want to come in on the point on the leaving certificate applied about which Mr. Harris spoke. I agree the leaving certificate needs to be looked at and we need to have a much broader idea of what success in schools looks like for all of our students. There has been some very good reform providing level 2 and level 1 programmes for the junior cycle but there is no obligation on schools to provide them. There is still a tendency in many schools to state that if people want special programmes, there is a special school to which they can apply. We need to have a look at this. Often our students are excluded from transition year, which could be a very beneficial less academically focused year. They may not be considered in schools where it is optional. We need to look at statutory obligations and, as Mr. Harris has said, not accept excuses for not running programmes to broaden the range of options available to students.

**Ms Lorraine Dempsey:** It was alluded to earlier that particular geographical areas do not have more children with autism but we have pockets of areas that are reluctant to open any form of special class. We also find with the applied leaving certificate that there are pockets of the country where schools perhaps see it as a lesser programme to offer to students and would rather leave it to DEIS schools. I do not think I need delve any further into what I am alluding to. For children with intellectual disabilities who might successfully transition from a mainstream primary school to a mainstream post-primary school, there comes a point because they do not have those adapted programmes available to them that the only option is to go to a special school. Straight off we have set them up for failure in this respect because it was not the plan

they set out with.

With regard to SENOs, what parents really want are advocates. We have a national advocacy service that parents contact but it deals only with somebody over the age of 18. Who do people go to? They go to non-government funded organisations, they go to voluntary parent support groups and they go to Facebook groups to get information in the hope that somebody will advocate for them when, in effect, the SENOs should have been set up to advocate and guide parents from preschool transition to primary school and not to leave parents with a list. At this stage, we should be smart enough to have a database of where the vacant places are and not have duplication of waiting lists for special classes.

The Department of Children, Equality, Disability, Integration and Youth is examining, on a national level, what is required in the context of parent supports. We are specifically looking to see what are the additional parent supports needed to be able to guide parents of children with disabilities in the absence of disability supports and key workers and identify who can help them navigate not only through the education system but also through the social protection system and all of the other schemes and assessments about which they need to know and bring them along on the journey rather than just give them a booklet containing information.

What we are really looking for under the EPSEN Act is education equality. Mr. Harris spoke about his personal experience. I have twins and I have spoken about them previously. They are 17 and they have very different pathways in education. They started off together in junior infants in a mainstream school but that is not where they will end up. It is bitter for families to have to make decisions on the basis of not having the right supports available to them to allow their children to continue in mainstream settings. If anything, this is something we need to address on a statutory footing.

**Senator Rose Conway-Walsh:** I have found this discussion very useful but its usefulness needs to be transformed into action, specifically in the context of what we do from here on in. From listening to the witnesses and from my dealings with people trying to access education, there is in-built protectionism in the system that supports the *status quo*. It will take a collaborative and concentrated effort to break it down. Ms Hart summed it up well when she spoke about the fight over a laptop for a child. This is exactly what goes on and it has to be tackled.

I have a question for Mr. Harris on investment. Does he know of any models of good practice for investment in the exceptional abilities of autistic children and adults? We are missing out hugely as a society by not investing in the exceptional abilities I have seen for myself in many autistic people.

**Mr. Adam Harris:** I thank the Deputy. She asked a question earlier that I will touch on. What a lot of this conversation comes down to, and why the EPSEN Act has not been commenced, is that while we are all in favour of inclusion and equality, sometimes what is not accepted in terms of the concept of disability is that it costs money. If we are serious about it, we have to be willing to invest. Representation is very important at all levels of the conversation and it has been something of an afterthought to date. If we were to make the one reform of putting people with disabilities and their families on the key decision-making bodies in this area, we would see pretty rapid reform. This is something else we need to think about.

On exceptional abilities, there is a resource and cultural element. Leaving certificate reform is part of it because if there were more opportunities to do short courses or gain points by pursuing interests it would create a huge opportunity. The most autism-friendly school in the world is

not inclusive of autistic people because they have scattered skill sets. People have to be able to work to their strengths as opposed to fitting within a system. Unfortunately, our system to date has been very much focused on a list of deficits, which aside from not working is catastrophic for people's self-esteem. We need to create within the education system a strengths-based model that identifies what a person's skills are and helps people to work through areas of education they might find challenging. To continue this conversation, the Centre for Talented Youth, Ireland does very good work and perhaps it could assist the committee further in this area. Autistic people are not just amazing at computers or science. Every autistic person has a skill, an ability and interests, and it is about meeting the person where he or she is at and using these.

**Deputy Rose Conway-Walsh:** I thank Mr. Harris.

**Vice Chairman:** That concludes our discussion. I thank all of the witnesses for coming before the committee and sharing their expert knowledge and insights. It has been a very productive and informative meeting.

The joint committee adjourned at 2.30 p.m. until 12.30 p.m. on Tuesday, 27 April 2021.