



Northern Ireland
Assembly

Committee for Employment and Learning

OFFICIAL REPORT (Hansard)

Inquiry into Post Special Educational Need
Provision in Education, Employment and
Training for those with Learning Disabilities:
Stakeholder Event

28 January 2015

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Members present for all or part of the proceedings:

Mr Robin Swann (Chairperson)
Mr Thomas Buchanan (Deputy Chairperson)
Mr Sydney Anderson
Mr David Hilditch
Mr Fra McCann
Ms Bronwyn McGahan
Mr Pat Ramsey

Witnesses:

Mr Eoin Murphy	Research and Information Service, Northern Ireland Assembly
Mr Alan Blaney	Post 19 Lobby Group
Ms Caroline Bogue	Post 19 Lobby Group
Mr Alan Clarke	Post 19 Lobby Group
Mrs Patricia Clarke	Post 19 Lobby Group
Ms Elizabeth Hawthorne	Post 19 Lobby Group
Mr Bob Hopkin	Post 19 Lobby Group
Ms Joanna Ireland	Post 19 Lobby Group
Mrs Julie Jamieson	Post 19 Lobby Group
Ms Claire Knox	Post 19 Lobby Group
Ms Cathy Mulholland	Post 19 Lobby Group
Ms Claire Smyton	Post 19 Lobby Group
Ms Shirelle Stewart	Post 19 Lobby Group

The Chairperson (Mr Swann): Ladies and gentlemen, I welcome you to the second session of today's Employment and Learning Committee. We are quorate, so I declare the Committee open. I thank the individuals who have come today for their efforts. I will ask the rapporteurs to report formally to the Committee, which, I have stressed, will be recorded in the Hansard report and fed into our formal inquiry. The format for today is that each table will have about five minutes to report, and then it will be open to the floor for any of the other tables to feed in with further comments. I ask those who wish to speak to raise their hands, and the Committee staff will provide you with the mic. When the mic is with you, you should give your name and organisation or the connection that you have with the inquiry so that it is read into the record.

If there are no questions on that, I will start with table 1, which discussed the choice and availability of educational courses in further education and vocational training. Will the rapporteur make themselves known and feed back?

Ms Caroline Bogue (Post 19 Lobby Group): My name is Caroline Bogue, and I am from Fermanagh. I have an almost-18-year-old daughter — she will be 18 in four weeks' time — who is at Willowbridge special school in Enniskillen. She has been diagnosed with autism and learning disability. I will just go through the points. I am not that sure how the format goes, but these are the issues that I find. I should also say that I am involved with the National Autistic Society, and I advocate for a lot of parents in a similar situation to mine, so I have a lot of knowledge of parents' difficulties with their child's transition to adult services.

I personally feel that there is not adequate provision that is appropriate and person-centred. What I mean by that is that, as I said, my daughter is almost 18 and is doing a post-16 course at her special school, and that involves her doing work experience one day a week and going to a training centre another day a week. This week she is tiling. I do not know how anybody else feels about that, but we find it ridiculous that our 18-year-old daughter, who will transition into adulthood next year, is learning to tile, which is totally unreasonable, because, as I said, she has a learning disability. She does not have any concept of shapes or sizes and her motor skills, both fine and gross motor skills, are very delayed, so it is totally inappropriate.

There are no adequate progression plans for my child's development. I have found that when we have gone to transition meetings — we had one last year as regards her moving on in two years' time — they did not know anything about my daughter. We had somebody from Education and the DEL careers person. The DEL careers person knew absolutely nothing about her, but the education board's transition officer would have had her statements over the years and really just knew what was on her statement but did not know what she liked or know her as a person. Everything was thrown back on to us as parents — "What do you think she'll do? What are her strengths?" — all of that. I would have expected that, as she spends a hell of a lot of time at school, they would have been able to tell us what her strengths are. We felt that that was lacking.

We have been told by both health services and school that, because of our daughter's learning disability, her choices are day centre provision or further education college provision. Our problem is that we have been told that she is unsuitable for day care because her ability is a lot higher than other people in day care who use that provision. However, she is very vulnerable, and we have been told that, if she goes to the college to do the life skills course, there will be no support for her at the college at lunchtime and unstructured times, there will be no transport for her to get to college and they cannot assure us that, if we got her a taxi, someone would go out to meet her from the taxi to get her to her class, not even just into the college.

The college is a huge, busy place for a child with a learning disability who has come from a very protected environment for the last 18 or 19 years. She would be thrown into that busy college on her own — if we can all remember what colleges are like — to try to navigate herself around to get to the room that she needs to get to. So, right now, at this point, my husband and I have no plans to send her anywhere, because it is not safe to send her to college, but we are told that she is too good for day care, so we do not have any other options. It is scary. I have met parents who have been in my position, and their children have been at home for the past four or five years and now do not leave the house. Those parents cannot leave the house either because their children cannot be left unattended.

The other thing that I have a big bugbear about, and I know that my five minutes is almost up, but I have to say this: our kids are at special schools for a reason. They are developmentally delayed and presently unfit to cope in the big world. Since Rois-Éireann has been doing the post-16 course, work experience has been in her timetable. When we saw that on the timetable, our understanding was, "Oh, my goodness. This is great. They are going to find out what she likes. She loves animals; she might get into a pet shop. She loves shops; she might be able to work in a shop, and it will be just fantastic". However, we as parents, and every parent with a child in special needs settings, have to find work experience for their child. So, if you are living in rural Fermanagh, there are very few options available to you. We were very fortunate this year because a friend of ours took her on, but, for him to take her on, he had to employ an extra staff member to mind her for the one day every week that she is there. I do not think that is fair on parents. It is too much to ask. A lot of people, particularly in rural areas, do not have friends who own businesses. We were just very fortunate. Surely those relationships should be made by the colleges or organisations, such as Mencap, because you have to look for the work experience with it as well. The parents should not have to do it. The colleges and schools should have already made those connections for the children when they go out to work experience.

I have overtalked here. There is a lot more that I could say, but I will let somebody else speak.

The Chairperson (Mr Swann): If there is anything that you do not get fed in, you can feed it back to us in written form, and we will take that as written evidence. Just quickly, is there any feedback from other tables on that subject? I am willing to open it up for a couple of minutes, or perhaps you want to leave it to your own table.

I move on to table 2, which discussed increased opportunities to work. Will the rapporteur make herself known? Please give your name and where you come from.

Ms Elizabeth Hawthorne (Post 19 Lobby Group): I have two boys with severe learning disabilities. One has just left school, and the other is leaving school this year. The one thing that would strike you about all our young people is that they all have very individual needs. They have such a wide range of abilities, and I see that even with my own two boys.

We would like to see the statement of special educational needs to stay in place until our young people are 25. We feel that further buildings on school campuses where the children can continue with their learning would be an advantage for them. We would also like to see a better collaborative approach between the agencies and between Education and Health.

For work, we would like businesses to get support from the government bodies and possibly incentives for them to take on our young people. Within that, we would like our young people to have access to mentors who can help them get into work experience or work placements and be there to smooth out any teething problems and provide support should they require it. They would need full training and guidance within that.

We would also like to see a directory online for signposting for parents so that they can have access to information. Information is not readily available, and we need a central source for that. There needs to be a consistency of approach over the whole of the Province and in the work area. We have a postcode lottery. As the lady who spoke previously said, people who live in rural areas have far fewer opportunities than people in urban areas.

Transport is also a big issue for us. A lot of our young people just cannot travel on public transport. They cannot cope with a bus that breaks down, a diversion that is in place or a bus that is not there on time. In our area, the Disability Action transport system is not guaranteed. It is not always reliable. If you have a child with autism who expects the bus to turn up, and it does not turn up or it is late, you have a major meltdown. So, we need something in place for transport. At the minute, it is mums' taxis. We have to be available morning and afternoon to transport them, and that limits what we as parents can do, especially if we are trying to hold down employment.

While there is a formal process in place for career guidance, it does not assist us, because the choices are so limited. The choices need to be more tailored. Our children are very individual, and we need a career pathway that reflects their needs.

Finally, to reiterate what the lady who spoke before me said, it is always stressful for us. We are always the ones who are left to pick up the pieces, to try to make the plans to get our young people into a place where they can continue with their education, develop and be happy. That is what we want for them. That is the feedback from our table.

The Chairperson (Mr Swann): Thank you very much. Do any other tables want to provide input on that subject?

Mr Ramsey: I just have a comment, Chair. We have always known this, but the worry, stress and trauma felt by parents and the development of their own medical problems because of that is a worrying trend as we progress into this issue. We have to reflect that in whatever recommendation we make. I take your point about a child being in an environment where they are content. We had that in our discussion as well. After being in an environment with their peers for a number of years, they move into the big bad world, not knowing. The concern from two or three of the parents here was that there really is no transition process that leaves them comfortable or confident. That is the punchline from them.

The Chairperson (Mr Swann): I have no further feedback on that.

Ms McGahan: On the back of Pat's point about the transition processes, in the constituency that I represent, Fermanagh and South Tyrone, you could have the best transition processes in the world, but there is still nowhere to go. I was at table 1.

The Chairperson (Mr Swann): That is the problem. It is the opportunity to work with higher and further education that most tables have touched on. Table 3 discussed future roles for HSC centres and day opportunities.

Mrs Julie Jamieson (Post 19 Lobby Group): I am a parent of a young boy with severe learning disabilities and epilepsy. We have been very naughty and have not really stuck to the programme. We have gone our own way and sorted out the world. We have a number of recommendations. We completely concur with tables 1 and 2 about the issues and difficulties facing parents and the impact on the family life of parents as they try to continue to care for young adults who have a range of issues.

We looked at the longer run-in time for transition. We agree with what Bronwyn said. Transition is grand. It is a great process, but, for a lot of our young people, there is nothing to transition to. My son is 13, and I know now that he will be going to a day centre. I know that; I do not need anybody in transition to tell me that. When he goes to the day centre, I want that to be more appropriate to his particular needs. It gets very complex around transition because children are moving from children's services to adult services, and it does not always feel that the right services are around the table while the discussions are going on. It seems to be that children's services are involved in the discussions, but adult services will be in charge of those progression plans that are going to be in place. So, it is a matter of making that more appropriate to the needs of our young people.

Parents should have more choice. Shirelle brought up individual budgets that are applicable in England and how we can access those, and that makes it a more personal service. It looks for more input from parents, but parents are making that input anyway. Claire and Elizabeth spoke about what parents have to do to make that doable. I have other children as well. When they get to the age of 18, they will make their choices and go and do what they have to do. For Henry, my youngest, it will be about me making sure that he can access the opportunities that he has to access. It is a very unfair situation. We look at those kinds of things as well. We are still going to do a lot of work around individual budgets, but it could be another opportunity. Individual budgets also mean that systems have to be in place that enable those choices to be made.

We talked about educational input up to 25 years of age, with the continuation of the statement. We also looked at day centre provision. If that is where young people have to go, then education should be going in there to those young people. That could entail the transfer of their individual education plans, but again, that goes back to statementing and where that should be.

Transport — getting young people transported safely — is a huge issue in any community but especially in rural communities. We did a little bit about outcomes-based provision as well. We have all this provision going on, but we do not necessarily know what it is doing or how it is doing it or who is overseeing it. Can we do something around that and can we look at those things? We know that day centres are covered by the Regulation and Quality Improvement Authority (RQIA) and all of that, but what kind of provision is there? What would a mapping exercise of day centre provision look like? That is a cross-departmental recommendation and we understand that.

For us, legislation was the ultimate aim. We probably need something that is going to support our children at least until the age of 25, if not beyond that, because that will allow them, maybe, to have another six or seven years of educational input, to have opportunities that are not available to them at present.

We talked a little bit about health outcomes as well, and I know that that has been alluded to. If day centre opportunities are quite sedentary, we are looking at obesity, diabetes and other chronic illnesses that are more likely to have an impact on people with disabilities. We are not helping that situation with the current provision. Parents are 20 years older when their children leave school, so that has an impact on their health. Stress and anxiety are huge issues for parents, and that was certainly something that came out of our research. There was a little bit of talk about the need for more teachers to have expertise in SEN provision and how we would see that into the future.

The Chairperson (Mr Swann): Does anybody else want to feed in on that subject?

Ms Shirelle Stewart (Post 19 Lobby Group): I have a 12-year-old boy who has autism and a severe learning disability and does not have any speech. I work for the National Autistic Society, but I am speaking as a parent. The way that my son is developing, it looks as if a day centre is going to be one of those opportunities unless there is something like individual budgets so that I could arrange provision myself. It is not that I particularly want to go down that route, but as the present structure stands, we have tried very hard as parents to get Calum out into the community to get him to have a social life and try new activities.

I feel that by going back into that system that does not continue with that lifelong learning, my son will regress in a sedentary day care centre that is not focused on him continuing to learn. His autism means that he is severely delayed in particular ways, but he has learned to do lots of things, albeit in a slow way. He has learned to go climbing and he goes swimming. He now has a communication device that enables him to communicate via little pictures that talk for him. It is about continuing that learning. I have seen him learn, but my worst fear in life for him is that, once he turns 18, not only does that stop but it regresses. I also think that we need to look at day care provision and what happens there. We need to be ambitious for our young people as well. That is the other thing: I see a lack of ambition out there for what they can achieve. I know, as a parent, that my son can develop with the right input and support. I very much want to make that appeal that we need to be more ambitious about what our young people can achieve, and we need to change the system and put choice into it.

Ms Hawthorne: I have a point about day-care provision. Somebody needs to ask how many kids with severe learning disabilities, particularly non-verbal kids, have been excluded from day care post-education. A number of the children who have been managed very well in the school system for the 19 years that they have been there are thrown into, for want of a better word, a day-care system that is unable to cope with them, and a lot of parents have to give up their working career to look after their children, who are excluded from day care. We really need to ask how many in Northern Ireland are excluded.

The Chairperson (Mr Swann): We will move on to table 4, which was discussing the coordination of post-school services for individuals.

Mr Eoin Murphy (Research and Information Service): I am the researcher for employment and learning here. We were covering transition, and one of the first issues that came up was the lack of a good working model for transition in Northern Ireland in that, initially, at the age of 14, a letter is sent out, and that is about the extent of it until much closer to the transition period at about the age of 16. The transition process itself is quite piecemeal and disjointed between agencies, especially at the second transition stage. In addition, individual plans that are developed during a transition process are more a tick-box exercise, with some support driven by availability rather than need at the end of it. So, parents find themselves almost being strongly encouraged to go along a certain path because there is an availability of services, such as day-care settings, rather than doing what they believe their child may actually benefit from.

Another issue that came up — it has been echoed by a number of the other tables — is the support at the post-19 transition. A young person will go into a day-care centre and end up in an almost sedentary process and they carry out the same process over and over again or go through the same classes. There is a lack of stimulation and learning for them yet they could benefit from a longer period in education and could benefit in the longer term. So, one of the main conclusions was to make the transition process more meaningful for the individual, with a more targeted and meaningful plan for the young person's development and an outcome that benefits them rather than sidelines them or puts them into a static position post-19 or post-25.

Communication issues came up quite a bit. At the transition point at age 14, a letter is sent out and you are informed that your child is now in transition. Communication then boils down to one or two meetings a year where the issues are discussed. As was mentioned, the information that is available is based on reports. It is very limited and the people who are helping make decisions on your child do not know your child and what they like. So, the onus is very much on the parents to force through and push ahead with their idea of what they would like their child's support to be, the same as the onus being on parents to contact services rather than the other way around where the service gets in touch with you. If you have an issue, it is up to the parent to highlight it and push ahead with making sure that there is some sort of outcome from it. There is also limited information provided regarding what support is out there.

What solutions were discussed? One that was mentioned is similar to what the Committee was suggesting in that, if a key worker is assigned to each case, it could be beneficial as you would have a single point of contact rather than any shifting changes, especially around the age of 18 or 19 at the second transition phase, when young people are suddenly shifting from the Department of Education through to the Health Department. That is quite a disjointed shift. A lot of the support that is available before that vanishes and it is quite a sudden straight-across transition. In addition, there could be something along the lines of either an individual or a system in place where there is an information hub and people are able to access information relatively easily or be signposted towards support that is available. So, if an individual key worker is assigned to a family or an area, they will be able to identify what services are available in a local area or the region to help support the child or the family. I think that Alan has a couple of additional comments.

Mr Alan Blaney (Post 19 Lobby Group): I am a parent and a school governor. I am quite active with Special Olympics, so I engage quite a lot with people with severe learning difficulties. My daughter has severe learning difficulties.

I found quite interesting something that the paper might not allude to but which we should look at. I think that there is an information gap. This year, there have been figures on how many kids with severe learning difficulties are going through the system. Interestingly, I wonder how many kids were going through that system 10, 15 or 30 years ago. Somewhere along the line, we will have the same sort of issue in that a lot of young people will be vulnerable adults with very ageing carers who will not be able to cope. More importantly, society and the community will not be able to cope either unless we engage now to make sure that this is managed. I think that this gap needs to be identified by this Committee so that the Ministers and the Government realise that there is a gap. I do not have the information or the know-how on how to get that information, but I suggest that there is a strong perception that the gap is quite high. That gap may also be classed as or considered to be a severe health issue that this Government or any future Government may wish to consider. It is the same as having a very sad illness such as cancer or AIDS.

I agree with table 1, which identified that that gap exists. I also agree that parents need to know where to go for the communication hub. Each community and each part of Northern Ireland has different groups up and running. There is different availability for our young people for social activities and educational activities. I find what was said about legislative changes very interesting, and that should possibly be considered.

With my daughter, I assume that the day-care centre will happen, however I know that she and a lot of her peers would really be challenged by working in the community, and being involved would help their self-esteem and their further development. I know that there are schemes that involve working in the likes of the Co-op, Spar and Tesco, however, having engaged with Mencap, I know that it stops. They are allowed to work only for a few hours a week if they get a placement, and it is the parent carer who goes out and gets them the placement. You are then told that they are not insured to cover you to be there longer. There needs to be a very clear ruling. Is that a local policy of Tesco or Co-op or the business leads, or is that information available to the community? I do not know whether that information is there, but it is thrown out. It is the same as being told that you need insurance for bouncy castles to go to people's houses. That seems to come under the health and safety umbrella. I do not think that it is there.

I do not have severe learning difficulties, and, if I wanted to volunteer for Cancer Research today, they would have me eight hours a day, every day. I can do that. My daughter who is 20 years of age cannot do that because she needs special insurance, not just employer's liability. There is a degree of what I class as discrimination. She is capable of doing that and giving something back. Also, quite a lot of people will turn around and say that it is based on money, but I suggest that it is not. If she is a young adult living without a carer and is on disability benefit and incapacity benefit — whatever this Government say that she is able to live on and cope with — you will find that she does not want paid. You will find that the child or young person just wants to be part of what they are. Money is not a big issue to a lot of kids with severe learning difficulties. When they have a job to go to, they like to be able to go to work and talk about it to their friends on FaceTime and Facebook or whatever it is they do. It is nothing more than that.

Just to finish off, I want to say that these are vulnerable adults now. Once they hit 18 and 19, they are adults living in our society. They will not have parents or carers there all their days and society will have to deal with that. They have a severe learning difficulty and that is a severe problem.

The Chairperson (Mr Swann): Thanks, Alan. Does anybody else want to feed into that? If not, we will move to table 5, which was dealing with the coordination of services within a locality and assessing community leisure facilities.

Mr Alan Clarke (Post 19 Lobby Group): I am a parent of a 17-and-a-half-year-old who is involved in the transition process and finding it quite a raw experience. Colleagues at the table have children of different ages and with special needs as well. We concur with what has been said at the other tables. Before I talk about community services, I want to pick up on one point about sharing expertise. There is a huge wealth of expertise in the special needs schools sector and again, it is about that transition, not just to employability, when you get beyond that, but to the basics, ie reading, writing and maths, and how that is communicated and taught beyond the transition period in the colleges or beyond.

Coming back to community services, we talked about trying to create more efficiency, particularly around the use of public buildings, and starting, again, with special needs schools as an example and the possibility of those school facilities being used beyond the 3.00 pm threshold, potentially by third-sector organisations. That would give a degree of control and safeguarding security so that there is a structure to how the school would be accessed, which would be for the protection of the schools and the safeguarding and protection of the post-19 people who might be able to access the facilities. I am thinking, for example, of schools that have playing fields. The one that my child goes to has a gym and assembly halls, and there are probably other facilities that could be of value to small groups wanting to come together to do things post-19.

At a local level, we talked about the councils and the idea of a hub in each council. It is about taking that concept of the information hub to another level and asking who is going to coordinate these services at a local level between education, health, the transition and the providers, assuming there are providers, which are very limited. Perhaps councils have a role there, working at a community planning level and linking back up to the Assembly as well and working with third-sector organisations.

We came up with a very simplistic example, which was the idea of a small number of specially adapted play parks across the Province. It does not always have to be the responsibility of councils; an example could be the Northern Ireland Scout Council, which has fabulous facilities at Crawfordsburn that are, maybe, not being used as efficiently as they could be. Other organisations' facilities could be coordinated to allow young people with special needs to have access to those facilities for fixed periods of time. Similarly, in the leisure centres, there could be the designation of a small number of centres around the Province for one or two hours a week of special time that special needs people can access. It is about collaborative relationships.

Another example of collaboration — I will use this as a mainstream example — can be found where I come from in Hillsborough, where the local controlled primary school has, in the same building, a community centre. The assembly hall of the building is used from 4.00 pm to 10.00 pm by the community centre, which also runs the outdoor pitch, the multi-use games area (MUGA) and some community meeting rooms purely as a community facility, but it is all built into the same building. There is a really good working relationship between the education board, the local council and the community group. It goes back to building those collaborative relationships between the statutory providers, the local councils, the community and, obviously, the parents and groups of parents so that they can come together to get the best that they can for small numbers of children.

Again, we discussed some of the assumptions, perhaps, in community facilities that the easy thing to do is to group special needs or disabled people all together. Quite a lot of the children, particularly those on the autistic spectrum, are very individualistic and have great difficulty in communicating and playing or working in social settings. We talked about the idea of awareness raising and training for front-line staff and community services, particularly such as for leisure centres, which a lot of our young people want to access.

We talked briefly about funding. It has to be a collaborative approach, given the difficult environment that we are in, and is about trying to get better use of facilities that are out there. Capital facilities are not being used as well as they should be. From a legal or legislative point of view, we talked about the fact that there is a commissioner for young people — I may not have got that title right — but who picks up that legislative interest beyond the commissioner for young people? Do they have some role in the debate about what happens after 19?

We talked about social inclusion clauses, and there was the comment earlier about making it easier for employers to give vocational opportunities and the extra support that is needed to enable employers to do that. There is probably a huge fear out there among employers about the idea of

taking someone with special needs or disability. I think there is a genuine fear there. Those are most of the points, and we concurred with the others.

The Chairperson (Mr Swann): Thank you. Does anybody else want to feed into that subject? If not, we will finish. Folks, I am not saying that you were rushed through your five-minute presentation, but it is good for us to get that read into the record from a personal point of view. If there is anything that you feel has been missed at your table that you want to submit in written form, we are still open to receiving that as part of the inquiry.

Thank you all very much for coming along and giving up two hours of your time on a Wednesday afternoon. The Committee is taking this seriously and intends, if necessary, to bring forward legislation on the matter.

We have another stakeholder event next Wednesday afternoon, on 4 February, in the Dunsilly Hotel, Antrim. Any person or organisation is welcome to attend. It will be the same sort of format. If there is anybody else, you can let them know that they can attend. Is there anything else? Are you happy enough?

Mrs Jamieson: Thank you for giving us this opportunity to come to speak with you today. It is good to be part of the process. *[Inaudible.]*

The Chairperson (Mr Swann): We are still gathering evidence at this point in time, so I would say that there will be further engagement down the line when we start to come forward with a report and recommendations.