



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Learning Disability Services: Department of
Health

23 May 2024

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Ms Liz Kimmins (Chairperson)
Mr Danny Donnelly (Deputy Chairperson)
Mr Alan Chambers
Mrs Linda Dillon
Mrs Diane Dodds
Miss Órlaithí Flynn
Miss Nuala McAllister
Mr Alan Robinson

Witnesses:

Mr Nigel Chambers	Department of Health
Mr Maurice Leeson	Department of Health
Ms Ciara McKillop	Department of Health
Mr David Petticrew	Department of Health

The Chairperson (Ms Kimmins): You are all very welcome. Thank you for your time today. In attendance, we have Nigel Chambers, head of learning disability and autism; David Petticrew, deputy director of community care for learning disability and adult safeguarding; Ciara McKillop, deputy director of community care for mental health and children; and Maurice Leeson, programme manager for partnerships, emotional health well-being, child and adolescent mental health and disability. Thank you all for coming. We have about 45 minutes in total for the session. Please keep your opening remarks brief — we have your very good briefing paper here — and then I will open the meeting to questions.

Mr Nigel Chambers (Department of Health): Good afternoon, Chair. Thank you for the opportunity to provide the Committee with an update on our work to improve services and transitions for people with learning disabilities. Today, we would like to provide an overview of the challenges across health and social care, the work under way to address those challenges and an overview of the direction of travel.

In the written briefing, there is an emphasis on adult learning disability services, but we would also like to provide an overview of our work to support children with disabilities, as both work streams are being progressed through the lens of transitions. Although those represent distinct and separate health and social care services, we must be cognisant that the level of need presented in adult services can be partly traced back to how well we support people as children.

In the briefing, you will note that there are several long-standing challenges, which are cross-cutting in respect of professional, agency and departmental boundaries. People with learning disabilities will experience entrenched physical and mental health inequalities. Those are compounded by lack of

access to primary and secondary care, as well as limited access to community mental health services bespoke to their needs. Day services and short breaks are stretched significantly to meet the current level of need in the system, and the conclusion of the European social fund significantly impacted on the delivery of community-based day opportunities. There is a lack of access to housing. That, in turn, can create increased demand for social care.

In children's services, there has been growth in the population and complexity of need of children with disabilities. That has stretched social care significantly. A correlating increase in the number of children with special educational needs has significantly stretched our healthcare provision across schools.

Transitions are a long-standing policy challenge, in that they are ultimately dependent on the availability of services and effective inter-agency working.

In March 2023, we established a learning disability task and finish group. It set out to finalise our service model for learning disability; to finalise our children with disabilities framework; to develop an overarching governance structure that would oversee the implementation of both products; and to progress a review of evidence, research and data.

In the past year, significant progress has been made to better understand our population, the presenting level of need, our capacity to meet that need and to identify the way forward to support those needs. The paper that you have been provided with sets out the work that has been completed to date or is nearing completion.

Throughout all that, engagement and cross-departmental working to date has been extensive. Officials have utilised a range of cross-departmental structures and initiatives to ensure that opportunities are maximised for public services to be delivered more effectively. We have engaged with and will continue to engage with families and people supported by our services to guide the way forward.

On our direction of travel, a draft model has been developed and shared with our range of stakeholders. That sets out a regionally consistent approach to service provision. It also outlines the work that the Department will progress to make that a reality. The draft model sets out a progressing transition through a lifelong approach: expanding health and well-being measures and supports to address entrenched health inequalities; to improve and diversify the level of support for carers and families; to promote meaningful lives and citizenship through the expansion of community-based day opportunities; to better support people to live in their own homes and improve our interface with housing; and to improve mental health outcomes and address behaviours of concern. Right now, work is under way to develop that model further through our cost implementation plan. A draft has been shared with the independent sector and the trusts for comment.

On children with disabilities, the framework has been updated to better connect with special educational needs services and healthcare. Throughout that work, we have remained cognisant that how we support children at home will impact on their ability to access the curriculum. Equally, how well we support children at school will impact on their presentation at home.

To date, a number of recommendations from that work have been progressed through the children's social care services strategic reform programme. Those include a demand and capacity review for short breaks; a review of early intervention and community-based supports is complete; exploring options to recruit and retain foster carers to improve our offer of not only short breaks but residential placements; a regional consistency review of children's disability services is complete; and, finally, a draft model for child and adolescent mental health services (CAMHS) for those with learning disabilities has been developed.

In conclusion, we fully recognise the scale of the challenges across services for children and adults with learning disabilities and the need for collaborative working. We are hopeful that the work set out in the paper and our contributions today will provide you with assurance that we intend to meet that challenge through the lens of evidence, research and data. As we move forward, it is also critical that we are guided by those who use our services and those who deliver them.

The Chairperson (Ms Kimmins): Thank you very much, Nigel. The briefing paper was very good, and we appreciated receiving it in advance of the meeting. I have a couple of questions. First, you mentioned that the consultation is under way. I appreciate that we have just had a relatively limited briefing on the budget. When, all being well, is the service model likely to be implemented post consultation? Have you had any conversations with your colleagues in the Department of Health's

finance department about what it will look like, given the current projections, or is that still being discussed?

Mr N Chambers: The direct answer to your question is that we aim to go out to public consultation on the learning disability service model this summer. At the moment, the implementation plan is being developed, and a costings exercise will be needed as part of that process. Once we understand the costings needed to implement the service model, we will be in a position to approach the Department of Finance. Taking into account a public consultation analysis and whether we go for an early implementation, if we consult in the summer and do the analysis by Christmas, the decision on implementation will be within this financial year.

The Chairperson (Ms Kimmins): OK. That is quite positive. Sometimes, implementation can be way down the line, so it is not too often that we hear that. A lot of factors are at play, particularly finance, but we hope to be in a different position and, potentially, have a different Government across the water, which may have an impact. Hopefully, if things stay on track, that will be good news.

A good level of detail has been provided to the Committee, and all members have had experience with the challenges that face children and adults with learning disabilities and their families. The briefing reflects a lot of what we hear on the ground, and it is really good that the Department has picked up on and recognised that and that, going forward, everything will be evidence-based, which is positive.

On the back of that, you outlined the work on transitions and said that the approach will be finalised in the coming weeks. Can you give some detail about the next steps? I ask about that because of issues that I have been dealing with in my constituency. We have Windsor day centre, Carrickore respite unit and other respite facilities.

A level of transition will be required, and you mentioned the community-based day opportunities. Yesterday, I met the Bolster Community, which is very much embedded in our community and provides excellent local opportunities for young people and adults with learning disabilities. I spoke to one young fella who has engaged with the service. Previously, it would not have been on the cards for him to live independently. However, because of his work with the Bolster Community and how it has brought him on, he will now live independently. There are really good success stories from the community and voluntary sector. When you talk about "community-based", is that part of the work with the community and voluntary sector organisations?

Will work on transitions be matched by an increased provision of not just day opportunities but respite? I am thinking particularly of young people leaving school. I mentioned Windsor day centre. I deal with families whose young people have very complex needs. They need full-time placements — five days a week — but are offered only three, and the families are heading into a crisis. I know that I have rolled a lot of things into one, but can you get my overarching question about the work on transitions, the next steps and what those steps will look like to match the provision to the needs?

Mr N Chambers: I will give you an overview of the day opportunities piece, and that will feed into transition and how we intend to operationalise our approach to transitions. One of the most significant challenges in effective transitions management is ensuring that there are good services waiting for a person when they turn 18. It is important to remember that becoming an adult is just one transition in a person's life. A person navigates a number of transitions throughout their life— entering employment, owning their own home, meeting somebody, starting a family and so on — and the principles of good transitions management are just as applicable at those times as when they are 18.

In the model that we developed, we adhered to National Institute for Health and Care Excellence (NICE) guidelines to ensure that we set out the correct process. Briefly, what that looks like is ensuring that there is sufficient access to information and support at an early stage. Part of good transitions management is enabling a person to understand what is available to them, and part of that is building up a menu of services. It is then about adopting a person-centred approach to transitions and ensuring that there is sufficient choice and control throughout the planning process. We are not fitting people to services but providing people with meaningful choice and control over what their life looks like after school and informing them of what the role of health and social care is in that space.

Within that, we have to draw on multidisciplinary input. Typically, in learning disability, conversations shift immediately to social care, such as what day centre a person will go to and what short breaks will be provided for the family. To be honest, social care services will probably make up the bulk of the care package that will be provided, but we need to draw in healthcare professionals as well. Adults

and children with learning disabilities will have a higher level of comorbidities than the general population, and poor management of those healthcare needs can constrain a person's transitions choice. If we do not manage things such as epilepsy and diabetes well in the community, a person's transition to a day centre will be limited, which means that day opportunities may fall off the table. It is about ensuring that we have healthcare professionals around the table during the planning process.

The other key pieces are about ensuring that somebody takes ownership of transitions. We have begun a costing exercise to ensure that each trust has transition workers — people who can support the person, help them to navigate our health and social care system and negotiate and advocate on their behalf. They do not sit outside the system but within it. We need to do other pieces at a departmental level to get to a place of really good choice and control throughout transitions. We can define the health and social care service, and we can expand day services and short breaks, but for things such as supported employment, volunteering, further education and access to housing, we have set out a body of work in our model that brings those partners together to ask, "How can we start to pool our services and commission together to ensure that somebody has the same life choices as we all had when we became adults?".

That is the aim and the aspiration. What is needed to achieve that is good cross-departmental and interagency working. Data is a huge piece as well. We have a system that acts surprised when people turn 18. We need to ensure that data flows from early childhood to throughout adulthood. Unless we know who is coming through the system, we will never have sufficient services waiting for them when they turn 18. Good data throughout transitions and into old age is important.

That probably covers a lot of what you asked. On day opportunities, briefly, the community and voluntary sector has a leading role. It has had a leading role in the expansion of the model since 2014. The European social fund was a catalyst for that, but the evidence is clear that community-based day opportunities offer superior quality-of-life outcomes and value for money. They provide a better service, but we recognise that, for some individuals, day care is still the best type of service and support, so we need to modernise what we keep.

I will hand over to Maurice.

Mr Maurice Leeson (Department of Health): I will talk about the regional protocol. We have had four regional workshops, three in person and one virtual, to develop a new approach to transitions. Those were part of the children with disabilities framework. We were conscious that transition is a very stressful and challenging time for parents, and we recognised that a lot of improvement was needed. As Nigel said, we have finalised the draft. We are looking at developing an easy-to-read version to help us to share and get responses to it. The data template is an important part of it, because, again, as Nigel said, we have to have better information in order to know when children are coming forward for transitions. We need that information from a very early age — from 14 — because, for some children with complex needs, it takes a number of years to put in place the arrangements that they need. If that is left until they are 18, there is little chance of it happening effectively. We have had a very good response to the development of the protocol. We did something this time that we had not done before. Previously, we tried getting children's services to work out how best to do transitions, and we then tried getting adult services to work it out. This time, we have done it collaboratively and produced a model that I am very pleased with, and I think that it will be a good basis for us moving forward.

The Chairperson (Ms Kimmins): Thank you. Sorry, David.

Mr David Petticrew (Department of Health): I was just going to say something from an adult services perspective. Obviously, that is a key service area as well. Over the years, a number of things have been proven to be fundamentally true, one of which is that good transition planning starts early. The point has been made that this is a real pressure point for families and a source of anxiety. That cliff edge, which can happen as young people and children transition into adult services, is really important. The service response for adults with a learning disability is different from the response for children with disability. That transition period is really important. People should be able to try different things to see whether they meet their needs. For families and the young person themselves, it is potentially a very anxiety-provoking time. The range of services is different for adults. Some families can be challenged by that, but an over 18-year-old has a different range of rights and a different range of things that they will want to do. A child with disability will see that in a different way.

The other thing to say is that there is really good practice in trusts at the moment. We should acknowledge that. However, standardising that good practice across the region is really important. We do not start from zero on this, but there is still scope for improvement.

The Chairperson (Ms Kimmins): Those points are important, David. There is really good practice, and it is about pooling that good practice and experience. The biggest issue for me is certainly the resource. That is where the problem lies. We are dealing with a situation where we have more and more young people coming through with more complex needs, and we just do not have the capacity at the minute. I am certainly very heartened by what I am hearing. It is really in tune with what we hear on the ground from families.

Most members around the table will support moving that forward in the time ahead. Thank you for answering those questions.

Linda is first on the list for questions. I must pop out for a few seconds.

(The Deputy Chairperson [Mr Donnelly] in the Chair)

Mrs Dillon: Some of what I was going to ask has been addressed, so I will not take you back over that. What you said has also created some questions for me.

Nigel, you will know from our previous conversations that there have been some challenges in my area, in the Southern Trust, around transitions from children's services to adult services, particularly where full-time care is required. That has had a knock-on effect on respite, families and everything else. That creates an awful lot of anxiety. I know that you are well aware of that. For me, the important bit is getting an understanding of how we will create equity regionally and ensure that, across the board, there is learning from what works, what does not work and what is good. Let us roll that out and make sure that it works for everybody. We have not done enough of that in the past. If we are getting to that place, that is great. I look forward to seeing what is in the consultation as well, but that point is really important.

Are there individualised transition plans? Are there standardised guidelines for creating those plans and for moving from children's services to adult services? If so, are they monitored and evaluated? You say that you need to be looking at transition from the age of 14. I understand that, but we all know that a lot can change between the age of 14 and moving into adult services. Yes, we should have at least a good understanding of the complexity of needs at the age of 14: whether a young person is likely to need full-time residential care, whether it is to be respite, or whether they will be able for day services — all of that.

How do we monitor? Are there individualised plans, and how do we monitor and evaluate them? That is my first question, and it is complex enough in itself, so I will not ask anything else at present.

(The Chairperson [Ms Kimmins] in the Chair)

Mr Leeson: Age 14 is the critical point. I take your point that things change, which is why it is important to keep an eye on the transition from 14 onwards. Plans are put in place, and one of the things that we have recognised in our current work is that we need to improve our monitoring of that. Therefore, we have put in place a data return that will enable us to get a better sense of how many children are coming forward at the ages of 14, 15 and 16. Therefore, we know in advance how many we are talking about and where complex issues will emerge. Those could be complex issues that require, for example, input from housing or from different providers. For us, the key to it, as you said, is to keep that monitoring very effective in order to make sure that we have the information to allow us do that and that, where problems and issues emerge that require direct departmental input, for example, we recognise that and get involved.

Mrs Dillon: How do we overcome that?

Mr Leeson: How do we —?

Mrs Dillon: Sorry. If you know what the problems are, do you have an idea of how you will address the challenges?

Mr Leeson: Apologies, that is why we were saying, with the actual —.

Mrs Dillon: My hearing is not great, apologies, so it may be to do with me.

Mr Leeson: Sorry. I will speak more clearly. We are saying that we want to have a much better and clearer —.

Mrs Dillon: Better monitoring of data?

Mr Leeson: Yes. We want to have a much clearer understanding of the number of children we are talking about and of where there are possibly emergent issues. Some of the complexities are challenging for us. We need to ensure that we have put in place an effective plan. If we require multi-agency input, which we often do, we need to ensure that the other agencies are all aware that children of a certain age will be coming and will need particular types of support. We need to be able to put those arrangements in place and to identify much earlier whether there will be challenges with that, be they financial or whatever, while making sure that, if there is going to be an issue, we identify it early and deal with it.

Mrs Dillon: That is helpful.

Ms Ciara McKillop (Department of Health): We have standardised the new regional protocol across the region, which should make it easier for those of us who are in the strategic planning and performance group (SPPG) to monitor those returns, identify areas of good practice and areas where improvement is needed and to be able to act on those quickly. Regional inconsistency is one of the challenges that families have faced up to now. Parts of the adult learning disability service model and the framework for children with disabilities are about regional consistency and how families, children and young people are supported through their transitions.

Mrs Dillon: OK. Is that now in place or being put in place?

Ms McKillop: The consultation is complete. We have some final comments to consider, and then we will move to the implementation stage.

Mr N Chambers: The adult service model still needs to go out to consultation. The components of transitions completely replicate what NICE guidelines set out. There will, of course, be consultation feedback about how we operationalise that. Good transitions management is already set out in the clinical excellence guidelines, but we need to move to implementing it. Data monitoring is a big part of that in order to ensure that you are subject to the same transitions process, whether you live in the Southern Trust area or in one of the other four trust areas, and that the trusts are using the right data in order to ensure that sufficient adult services are waiting for a person when they age into adult services. Additionally, data needs to flow centrally into the Department in order to ensure that we provide sufficient resource to meet the level of need that is coming through the system.

In everything that we talked about, we focused a lot on the transition to age 18, which is a very important transition. The transition that keeps parents awake at night, however, is that of who will look after their young one when they are not there. It is the same process. We need to use that data consistently throughout our delivery of adult services in order to ensure that there are meaningful accommodation and shared caring solutions for families as they get to the end of that caring journey together.

Mrs Dillon: I really appreciate that, and thank you for addressing it. That is of concern and has been raised with me.

I will ask just one other question, because a lot of people probably have a lot of questions. This question is about parental or caregiver involvement. How has that been done, and how will it be done continuously in order to make sure that what we implement works and delivers for the people it needs to deliver for? That means the young people who are moving into adulthood and beyond and the people who care for them, whoever they may be. Monitoring that is important.

Mr N Chambers: Where carers and families are concerned, we are setting out via the service model the idea that, first, we need to better recognise the voice of carers, both in care planning and in the delivery of our services. Secondly, we need to start better meeting the healthcare and social care needs that carers present. We are doing that through a few different pieces, all of which provide conduits for families to become more actively involved in care planning for their loved ones. We

always need to balance that against the views of the person who is being supported. Our own parents probably had very different ideas for us than we had for ourselves, so this is about ensuring that the voice of the person with the learning disability is not lost in the care-planning process.

We have set out in the service model that there needs to be a single point of contact for families, whether it is in healthcare or social care, but families need help. We need to simplify our complex health and social care system. Families should not be sitting on the phone half the day getting bounced about by the system, trying to find advice and support. We are saying clearly that trusts need to actively involve families and carers in the planning and decision-making about their loved ones across all elements of care. Throughout transition plans, families should be offered care support assessments, and those should then inform the development of care support plans. That is about meeting their needs as well as the needs of the person they are supporting.

There is a big piece around accessible training information and support. Sometimes families want a central point that lets them know what services, supports, guidance and help are out there. The model is about being able to centralise that in an accessible place. There is a big piece on short breaks, and that is about ensuring that we provide the correct level of service while diversifying that service. A lot of focus is on residential short breaks, and that is an effective service, but we need to grow our shared care arrangements, our shared lives service and adult placements. That is where host families can provide a day to an activity-type service or a short break to a person with a learning disability.

The other components are around managed budgets. That is probably one of the best tools to allow families to have a much more active role to dictate the type of care — the when, the how and the what — that comes through the door. We are doing a piece of work on managed budgets to try to make those elements a reality. It is about taking real control of a budget to set out, "How will my care needs be met, and how will the care needs of my loved one be met?"

Mrs Dillon: Thank you. That is really helpful. I would like us to get an understanding of what the single point of contact looks like and what it will deal with. That is the dream of every person who comes to me who has a young person or an older person with additional needs. They are saying that that is their issue at the moment. In days gone by, you would have had a social worker attached to almost every person with additional needs, and they were the single point of contact. We do not have that now, and I am not sure that we will ever see that again, given where we are at the minute with social workers. That would be the ideal, but we need that single point of contact, because families are doing exactly what you said and are pulling their hair out. That means that by the time that they get to somebody who can help them, they are already so frustrated — that person is getting everything — which is not where you want to be either.

Mrs Dodds: Thank you for that. It is important that we understand what the model might look like in the future. All of us here have met parents who have young children with special needs who do not know where to go next to find someone who will help them, or they have a young adult in the same position. I want to speak about someone who is transitioning from adult services at the age of 65 or 66 into senior services. I have come across cases of that recently, and they have been devastating for the families that are involved. It can be a run-through life's journey, in many ways.

My first question is about the provision of services for children with additional needs. We have experienced huge confusion and chaos in getting young children with enough information around them into an appropriate nursery placing. Those services have broken down because of either the health visitor or whoever it is who should be providing that information. I am told that some of those children cannot be placed because they do not have a statement or the statements have not come through in time etc. My first question is about improved working across the board between Health and Education in order to try to prevent that year-on-year chaos for preschool children who need a special placement at school.

The other end of that is that if you have a young person with a disability, you find that they are very well looked after in school until the age of 19, but what happens then? Personal friends of mine who have a young person with a disability have been offered two half mornings in a day care centre. While we are talking about how we might look at this in the future, we have to be honest with people about the fact that provision in the here and now is very sketchy and that much of that caring and responsibility is thrown back on to parents almost 20 years after their child was born. I want to try to understand. For example, in England, there is legal provision for young people with disabilities right up to the age of 25. Have you looked at that in this context, and, if you are not going to introduce it or recommend that it be introduced, why not? It seems that that would be one of the things that would

help to inform what that young person's life would look like and would give them more time to develop and more time to be with people who can help them with their understanding.

I also want to talk about that transition at a later stage in life, because I have had some devastating cases about that. I am asking about preschool provision and why should we not have legislation to protect young people up to the age of 25. I note that there is currently a campaign. I know of a mum — her son is called Caleb — and she said that her child is not at that stage yet, but she is worried about what he will do. I have no idea whether any of this will be in place — transition workers or anything like that — but it seems that giving such young people legal cover until the age of 25 is quite important.

Mr Leeson: I will maybe tackle your question about information first. To give one example, we have produced a resource called 'A guide to help you on your Journey through Disability/Additional needs'. It was produced with parents and is to help parents who have a child with a disability. It was written by parents to literally take you through the life course and explain a bit about different professionals, their roles and resources. We have developed that while very much picking up what you said about there about often being a dearth of information, with parents not knowing who to turn to or possibly wanting to explore some of the things themselves before they approach professionals.

Where preschool provision is concerned, we run the fair play and the holiday grant scheme in partnership with the Department of Education. Fair play provides additional support to day-care providers who want to take a child with additional needs but who may need, for example, extra hours, an extra piece of equipment or something else to enable that placement to happen, because without that support, the placement would not happen. We do that, and we also have Family Support NI, which is our online portal for all services.

Mrs Dodds: All that is fine, and many people who are working in the field will understand that, but there is clearly a breakdown somewhere. There is clearly a breakdown in the communication about children's needs, because, otherwise, we would not have a scramble at preschool stage to have children appropriately placed or with non-verbal children being offered places in a mainstream nursery. There is a breakdown somewhere in that communication, which all the plans in the world for the future will not solve for the here and now, and parents are really worried about it. I can never manage to get to the bottom of why that breakdown has occurred, with the result that the health visitor does not pick up and recommend further.

I have just a further question about that. I visit a lot of special schools, and they tell me that they have many more children they are being asked to take. They are always being asked to take more and more children, but they are not offered any more slots from speech therapists, physiotherapists or occupational therapists. I know that this is about planning for the future, but, if we do not tackle some of these problems, they will not go away.

Mr N Chambers: We referenced that briefly in our briefing paper. We could probably have another session with you to talk about everything that we are doing in the special educational needs space. There may not necessarily have been a breakdown in communication, but there has certainly been a missed opportunity to use the data that we have to inform long-term planning.

You are correct that health visiting is probably one of the most consistent services through which we can pick up the developmental today, whether it is gross or fine motor skills, speech and language or additional needs. Most children will get most of their health visiting appointments. By the time that a child is aged two, there would be a fairly good understanding of any form of delay. I think that over 90% of health visiting appointments that check for those happen in that year. A significant data set is built up with the red book, which outlines the number of children who have developmental delay and where they have been referred to.

We are undertaking a fairly rapid piece of work with Business Services Organisation (BSO) and the health intelligence service to see how we can use that data better in order to make projections about special school admissions and placements. We are working with Education in that process. Not every child who has developmental delay has a special educational need, but we can at least look over the past number of years to build up some fairly robust assumptions about a level of presenting developmental delay and a special schools placement. That is a necessary component to ensuring that we have sufficient places available in special schools.

The second component is the provision of therapeutic supports. The population of children with special educational needs has grown sizeably since 2020. I think that it is at around 70,000 children,

and over 20,000 of those have statements. Historically, we worked across 38 or 39 special schools, but, in response to the growth in that population, children are now being allocated places through specialist placements in mainstream schools. For some children, that is the right environment. They have access to the curriculum, but in dispersing the health and social care workforce, particularly allied health professionals, we have hit the limit of that workforce's ability to work across that number of schools.

For the past number of years, trusts have had to operate a model of clinical prioritisation. Minister Swann, in his first term, put an additional £2 million to £3 million into allied health professionals to increase the workforce, but we are really at the point now where this is not a more money-type solution; this is about the reform of the allied health professional model. We need to change how we deliver therapies, because the trajectory is very much that we will continue to place children in mainstream schools. That means that we need to provide therapy in a different way in order to ensure that those supports, particularly speech and language and OT, are being provided to children with special educational needs.

Mrs Dodds: What about legislation for those people up to the age of 25?

Mr N Chambers: Extending the window for a transition was reflected in the children's services review. We are very much still exploring that as part of progressing the work on transitions in the protocol. You are right that it provides that longer window for a transition to be dealt with in a much more phased and managed way. It provides the opportunity, as David said, for the supported person to try things that they maybe like and do not like. At the other end, the risk is that you simply move the cliff edge from the age of 18 to the age of 25.

We are certainly exploring that. We can explore whether legislation is required to make it happen, but we are cognisant that we need to extend the window for transitions so that there is not such a sharp change in a person's life when they become 18.

Mrs Dodds: To go back to the legislation, I will say that young people should have rights. If those rights were more clearly defined in legislation rather than in the hope that trusts will provide equality of service, it would improve the ability of those young people to transfer more successfully. We all have constituents who are very worried about young people and what happens next. We should allow those young people a longer period to transition in and give them rights while they are doing that. I have some personal scope on that, but it is really important.

The other aspect is the transfer at age 65. I have dealt with some cases on that recently, where people who have been in day care and have been with learning disability services right throughout their adulthood suddenly have nothing. That has been extremely traumatic for elderly carers and for the persons concerned. In one of those cases, I could never work out what the problem was with being 65 one day and 65 and a day the next and having to leave everything that you have known for the past 30 years.

Mr Petticrew: I was genuinely surprised when you raised that. It has been at least 15 years since I was a social worker in the community, and I thought that that had been put to bed a long time ago.

Mrs Dodds: Not at all.

Mr Petticrew: I really did.

Mrs Dodds: Not at all.

Mr Petticrew: It is based on people's needs. There is no real difference between 64 and a bit and 65. It has to be based on whether the facility can safely meet people's needs. From human rights and equality perspectives — trusts have been challenged on those — usually the outcome is a reassessment and the person continues in that setting. That may not have happened in the case that you described, but, in my experience, the hard and fast rule that on your 65th birthday you have a leaving do is from the old world.

Mrs Dodds: You have a bit of cake and a party and away you go.

Mr Petticrew: Obviously, however, you have seen that that continues. Nevertheless, when trusts are challenged on it, they usually revisit that decision and it changes.

Mr N Chambers: There are a couple of other components to that. Currently, with day services as stretched as they are, placements will be prioritised for those who are in the family home, because that helps to maintain permanence at the placement. Additionally, then, there is a financial tension for trusts in terms of conditions of service for care homes. On average, a care home placement for a person with a learning disability can cost around £200,000 per annum. At that point, the expectation from trusts, as commissioners of a high-cost placement, is that meaningful day activity should form part of the package that they are commissioning. That does not necessarily always happen. I have met families that are going through the same issue that you described, whereupon moving into a care home, people the individual has known since special school and throughout day care are suddenly not part of their life any more. The maintenance of friendships and routine is very important.

Mrs Dodds: I am sorry. Just to be clear, the person was not moving into a care home; they were remaining in the family home. However, the likelihood is that, sooner or later, that will break down because of the lack of placement during the day. Therefore, to use a phrase, we will be cutting off our nose to spite our face in the middle of it all. I do not understand why you are not aware of that. It is happening — genuinely.

Mr Petticrew: I know that, in the past, the Regulation and Quality Improvement Authority (RQIA) was involved in those types of discussions on registration and status and on whether the facility could meet people's needs. Truthfully, I felt that that was no longer an issue in communities. It has not come to my attention recently. That is why I was surprised that you raised it. I thought that it had maybe gone away.

The Chairperson (Ms Kimmins): I am conscious that we are well over time and that three members are still waiting to ask questions. The RQIA is coming here in the next couple of weeks, and it may well be worth getting a bit more detailed information on the specifics of that matter.

Mr Robinson: The discussion has progressed, so my question is more of a comment. Last year, Diane and I met the principal of a special school who expressed her genuine fears and all sorts of trepidation for her pupils who were transitioning from school into day centres. One of her biggest fears was about the fact that they were moving into mixed-use day centres where there were adults, including, perhaps, 60-year-old men. That is no disrespect to any 60-year-old men, but she had a genuine fear that safeguarding might not be at its best. How will the model strengthen safeguarding in day centres?

Mr N Chambers: There are two things to say to that. One is that there are limited transition choices, so there is an inevitability of their going to a mixed day-care service. We are promoting in the model the expansion of community-based day opportunities so that the type of day activity that is provided to people is supported and far more reflective of what they want to do and with whom they want to do it. That is about ensuring the availability of services. David, I will pass over to you to talk about regulation. Day care is a regulated service. It is inspected by the RQIA.

Mr Petticrew: Is your concern about the safety of young people in such a facility?

Mr Robinson: Yes.

Mr Petticrew: A risk assessment would be completed. If there were a specific issue with interfaces, where different bits of the building are shared, I assume that the facility manager would complete some sort of risk assessment. It is really hard to know what would happen without knowing the real circumstances that you are describing. In my experience, children and adults do not tend to mix, but is the experience of them mixing what you are talking about?

Mr Robinson: That was the principal's experience.

Ms McKillop: It is young adults who are leaving special schools and moving into day centres with perhaps a range of older adults. All facilities that are inspected by the RQIA will have adult safeguarding procedures that they need to adhere to, such as vetting staff, controlling who comes in and goes out, and risk-assessing all the people who attend the day centre. The dynamic is that attention will be paid to that and to all the components involved in making sure that the activities are

appropriate and that the groups that people are in are appropriate. There will always be higher staffing levels by virtue of the needs of the people who are attending, so it is unlikely that young people would be on their own for any significant time.

Mr N Chambers: There is another component to it. We will be leaning heavily on community-based day opportunities in order to provide better outcomes for people, but we still need to retain day care. We certainly need to consider and cost the modernisation of day care, while being cognisant of the fact that some of our services have not seen any significant investment for a number of decades. There is a need to improve the environments. A number of trusts have told us that they see higher levels of complexity of need coming into day-care centres. That necessitates higher levels of staff so that people are supported in order to meet their needs. It also, however, sometimes leads to lower compatibility among service users, which can turn a centre that has, say, 20 people into a 10-person unit, because people are siloed. Safety, environments and the skills mix of people are all components of what we are thinking for day care.

Mr Robinson: Interesting.

The Chairperson (Ms Kimmins): We also have the adult protection Bill, with which we will be dealing.

Nuala, thank you for your patience.

Miss McAllister: You are OK. It is an important issue. Thank you very much for the briefing. I will focus on two areas. One is residential and respite care, while the second is co-production, with which I will start. There are some excellent day centres in our community that run themselves, with some funding coming from their trust. One is Newington day centre in my constituency of North Belfast. It is often left chasing the Belfast Trust for information and about promises and commitments that were made, not because of funding issues but for reasons that we cannot quite get to the bottom of. That creates a lot of uncertainty. It also breaks down the trust between the trust and the community sector. Furthermore, it highlights the fact that some organisations in the community, such as Newington, are run excellently and offer fantastic services. What would a co-production model look like if it were based on best practice from evidence that the community, rather than government, has?

Ms McKillop: Part of the children's social care services reform programme is about how trusts, commissioners and the Department work more effectively with the community and voluntary sector and with parents, carers and service users. We have two work streams. One is about how we more effectively support families together, and the other is with the Reimagine Children's Collective.

Miss McAllister: Newington day centre is —

Ms McKillop: Adults, mainly.

Miss McAllister: — for adults.

Mr N Chambers: I will cover the adults piece, and then Ciara can cover the children piece.

We have worked very closely with the community and voluntary sector on the work that we have progressed over the past number of years. That work has built on a fairly significant amount of engagement with the sector. During the COVID response, the sector very much guided us on developing guidance, getting financial support and how we interact with housing. We built on that collaboration by developing an uplift package for supported living to ensure that those who were lowest paid were paid a fair and competitive wage. That was collaboration and co-production viewed through the lens of responding to a crisis. We have built on those relationships to involve the sector. The Association for Real Change (ARC) is a key member of our task and finish group, and it has enabled us to engage with over 50 voices — independent sector providers — across a huge range of services, including nursing and residential, supported living, day activity and short breaks.

Earlier this year, we worked with the ARC and its providers, and, most importantly, with the people whom they support, to deliver an event on meaningful lives and citizenship. That involved everything around how we enable people to have a meaningful day. Day services are a big part of that: how we provide day opportunities and manage budgets. We then started tapping into some cross-cutting issues around transport, which is a huge piece, to determine how we connect the dots. We tapped into

benefits as well. One of the key pieces of feedback that we got from the event back in March is that there is a reluctance to get involved in day opportunities, because they can result in people receiving a lower income. We need to address that barrier. We will very much continue to be guided by the people who use our services. We are working very closely with the independent sector, and, via the Association for Real Change, we have been sharing iterations of the work that we have been progressing. We want to get feedback, and we will actively involve the sector in the development of the implementation plan.

Miss McAllister: If it has not engaged, can I invite you to come along to Newington day centre to see the fantastic work that it does in the community? There will obviously be a difference between urban and rural day centres, and we have to recognise that. Where there is fantastic work being done, such examples can be built on, but, hopefully that day centre is engaging with those 50 voices.

Mr Petticrew: That is a really important point, because we want to grow the menu of services to which people have access, and we want to improve and make that model take root in Northern Ireland. We have to engage, but we also have to treat the community and voluntary sector as a real partner, and anybody from the community and voluntary sector would say, "You haven't done that in the past". That partnership approach, which, at times, we have really tried to drive forward, has been challenging. It has been at the heart of this new piece of work, and we have had really good engagement. It has been a very positive development to help us deliver what we have talked about today, which is a new model that works in a more flexible way and is, hopefully, better value for money and gives people better choice in the community. Partnership is therefore at the heart of it.

Ms McKillop: I will come in there quickly. The Reimagine Children's Collective, under the Children's Social Care Services Strategic Reform Board, is about learning from community organisations about what works really effectively. It is about how we can scale and spread that work, about what works locally and has worked here, and about how we share that work.

Miss McAllister: I also want to talk about the Iveagh Centre. When departmental officials were at the Committee on 21 March, there was an acknowledgement that delayed discharge — on which judicial reviews (JRs) had to be taken on behalf of families and with families — should not have happened and that such instances are regrettable. One of the outcomes is what the model and framework will look like. To be perfectly honest, however, I am still not 100% on board, because of the experience that families had, particularly those with relatives in the Iveagh Centre who have awaited the discharge of their loved ones. You can understand if someone might feel like waiting until young people transition to adulthood, because then it is not their problem any more. That is how we get them out and free up the bed space. It is really sad that it has come to that. Where are we sitting now with the Iveagh Centre?

Mr Leeson: I will answer that. That group of children have all, bar one, transitioned out of the Iveagh Centre. One young person from the group that you are referring to is still there. A placement is now available for that young person, and they are transitioning to it. We expect that to happen over the next month.

Miss McAllister: Is that because they are transitioning to adult services or because there is provision in the community?

Mr Leeson: That person is transitioning to a resource in adult services, yes.

Miss McAllister: Was it the same with the other four? Did they transition to adult services?

Mr Leeson: No, there was a range there. There is no doubt that part of the issue with Iveagh was because there was not adequate provision in the community to meet all the needs of the young people concerned when they were discharged. That is part and parcel of what we are trying to address through the framework for children with a disability. We are saying that we need to look at this in the round. We need to improve the early support that is available to families. We talked a wee bit about that when we discussed how we try to support children with disability into day care and by providing holiday schemes. We have developed ideas for how we intensively support families, improve the short breaks and also ensure that we get our residential model for children with disability right. We are therefore trying to take a more comprehensive look and recognise that we need to do as much as we can to ensure that children's circumstances do not deteriorate to the point at which they need something such as the Iveagh Centre. If they do need Iveagh, however, they certainly have access to

it, and we also have services that will support them with their discharge so that no one is stuck there when their treatment is finished simply because there is nowhere for them to go.

I will be quick, because I am conscious of time. I just want to say that we are doing a lot of work on intellectual disability child and adolescent mental health services (ID CAMHS), and Iveagh is included in that. We are working to improve that service as well.

Miss McAllister: Thank you. I will follow up in writing with more questions, because I am conscious of time.

The Chairperson (Ms Kimmins): We are well over time, and we have another briefing after.

Miss McAllister: I have one final question. You are here, so I am taking the opportunity. We are six weeks away from the closure of Muckamore Abbey Hospital. Where are we at with its current residents? Muckamore is not entirely within your remit, but I want to raise the issue at every opportunity.

Mr Petticrew: I can say something about that. The commitment is for Muckamore to close in June of this year. Given where we are at at the moment, that will be challenging. The Minister and the Department have an undertaking to engage with the families first on the next steps. When that happens, we will write to the Committee and update it on what will happen next with the process. Given that there are currently 24 people in Muckamore and it is very close to June, decisions have to be made and discussions have to happen, clearly.

Miss McAllister: It looks as though it cannot close by that date if there are still 24 residents. I feel that it is a bit late to be leaving it until the start of June to tell families that.

Mr Petticrew: That is the engagement and discussion that has to happen.

Miss McAllister: I understand that it may not be within your remit, and I am not trying to apportion blame, but, when we are coming so close to the end of June, when Muckamore was earmarked for closure, and those people and their families have already been through so much, there needs to be better communication on when a decision needs to be taken.

Mr Petticrew: There will be further engagement with families in the very near future for the very reason that you have set out.

The Chairperson (Ms Kimmins): Finally, I have Danny online. I know that he is having a few technical issues, so his camera is off, but he is there.

Mr Donnelly: Thank you very much, Chair. A lot of the questions that I was going to ask have already been answered during the discussion. I am really heartened to hear the word "meaningful": helping people live meaningful lives and citizenship, with meaningful day opportunities. The word keeps coming up again and again. It is great to hear that there is recognition of the cliff edge for transition and that a lot of work is going into that at the minute.

Does the Department take any account of the provisions of the United Nations Convention on the Rights of Persons with Disabilities when taking decisions on learning disability, in particular article 9 on accessibility and article 19 on living independently and being included in the community? Did you hear me there?

Mr N Chambers: Yes, I did. It is quite the question to finish with. Your question is about accessibility and living independently. Accessibility flows throughout the work that we are doing, because part of what we need to do across the entirety of Health and Social Care is to enable a person with a learning disability to use the same health and social care services that we do to a degree. We cannot create a segregated system or a segregated set of health and social care supports for people with learning disabilities, but we do still recognise that, at times, specialist support is the right service for them. A big part of it is about equality of access. We are doing a big healthcare piece, in the context of the review of learning disabilities nursing, on how we use that specialist resource across primary and secondary care so that people with learning disabilities can use the same NHS as we do.

Independent living is a challenging space, because Health and Social Care has such an important role to play in it, but we do not build houses or provide housing support services. Equally, however, without health and social care provision, housing units and support services will not enable somebody to have a home and live independently. To try to start getting through a lot of challenging issues, we have set up a supported living work stream as part of the social care collaborative forum, with the Department for Communities, the Northern Ireland Housing Executive, the RQIA and seven large independent-sector providers. The forum is starting to look at developing a vision for supported living: of how we enable people with a learning disability to access their home and have choice and control over whom they live with and of the role of Health and Social Care in meeting their needs.

There are some really difficult things to work through. We need to understand best practice for the supported living model. We need a definition. It is such a wide service and includes such a diversity of need, services and staff that we need to define it. We need to understand what we have been commissioning to date. Across all five trusts, supported accommodation is the leading area of spend. Health and Social Care is being pulled more and more into the accommodation space, so we need to establish good boundaries with housing providers. We need to look at what housing providers and Supporting People provide, at what we do and then at what falls in between, all of which needs to be looked at in the round in order to support somebody to live independently. That work stream has just been established — it met for the first time last week — but supported living as a service has been developing in Northern Ireland for well over 20 years. It is therefore about trying to build on what works.

Mr Leeson: Throughout the work on the framework for children with disabilities, we used as a guide the United Nations Convention on the Rights of the Child, particularly article 3 on the best interests of the child, article 5 on parental guidance and a child's evolving capacities and article 23 on children with disability.

Mr Donnelly: Those are fantastic answers. I am glad to see that a lot of work on supported living is starting to be progressed. I was involved in supported living years ago as part of my nursing training, and I entirely see the benefits of it.

There has been a bit of discussion about what is available and the struggles that some families have. Are there significant differences among trusts when it comes to delivering services for people with learning disabilities?

Mr N Chambers: For the adult programme of care, we undertook a review of data across health and social care trusts. As part of that review, we mapped the services that they provided and commissioned. We found that, across the trusts, there were 47 service types, of which only 10 were consistently delivered. When I speak to families, they talk about a postcode lottery for services, and the data validates their position. That is why the first key aim of the service model is to provide a regionally consistent service for people with learning disabilities, their families and carers.

Mr Leeson: In children's services also, as part of a process of agreeing to move towards having one consistent model, we have mapped how the trusts provide services.

The Chairperson (Ms Kimmins): Danny, can you keep it brief? We really need to move on. I know that you have waited patiently.

Mr Donnelly: No problem. If you do not mind, Chair, I will raise one last thing. Nigel mentioned the impact of the European social fund cut. Can you tell us about specific impacts that that has had on opportunities across Northern Ireland?

Mr N Chambers: Throughout the concluding phases of the European social fund, we worked closely with the sector, the Department of Finance, the Department for Communities and the Department for the Economy to prepare for that fund's conclusion. You will be aware of the launch of the Shared Prosperity Fund (SPF) and the funding that will potentially come from that. We worked to the worst-case scenario, which was that the applications of those who had received European social funding would not be successful under the SPF. We tried to get an understanding of how that might affect their organisational sustainability. We found that a number of organisations were dependent on that European funding to such a significant extent that, without a replacement fund in place, they would fold fairly shortly after it ended.

To provide a level of assurance and confidence to the providers who received match funding from trusts, we worked with the trusts to ensure that, regardless of the SPF piece, the match funding, which, I think, accounted for around £5 million, although I will need to double-check the figure, would be in place for those funders and would roll into the new year. Over the past 12 months, we have seen that that has an impact on the delivery of day opportunities. Although the SPF replaced a fairly sizeable amount of the European social fund, providers were being paid to do something else. The programme is focused more on getting people into employment than on providing the wider types of services that build a journey to employment but are less focused on those targets. Simply put, those providers have been paid to do something else and have had to go back to the trusts to renegotiate what service they can provide with a lower amount of money. At an anecdotal level, if a service had been providing a day opportunity service of a full day, they may have rolled that back to a half-day service, freeing up their afternoons to focus, for example, on their Shared Prosperity Fund work.

We can certainly see that a reduction in funding has resulted in a correlating reduction in service.

Mr Donnelly: Thank you very much for allowing me that extra question, Chair. Thanks to the witnesses for their response.

The Chairperson (Ms Kimmins): Thank you, and apologies for having to cut you short.

Thank you all. As you can tell, we did not anticipate that we would have as many questions, but that shows you just how important the issue is. Thank you for your time. It has definitely been very useful. I am sure that we will see you again in the not-too-distant future.