



Northern Ireland
Assembly

Committee for Health

OFFICIAL REPORT (Hansard)

Autism (Amendment) Bill:
Health and Social Care Trusts

18 November 2021

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Mr Colm Gildernew (Chairperson)
Mrs Pam Cameron (Deputy Chairperson)
Ms Paula Bradshaw
Mr Alan Chambers
Mrs Deborah Erskine
Ms Órlaithí Flynn
Mr Colin McGrath
Ms Carál Ní Chuilín

Witnesses:

Ms Moira Kearney	Belfast Health and Social Care Trust
Dr Sarah Meekin	Belfast Health and Social Care Trust
Ms Jayne Colville	Northern Health and Social Care Trust
Ms Ciara McKillop	Northern Health and Social Care Trust
Dr Mandy Irvine	South Eastern Health and Social Care Trust
Ms Julie Kilpatrick	South Eastern Health and Social Care Trust
Ms Denise Carroll	Southern Health and Social Care Trust
Dr Liz McMonagle	Southern Health and Social Care Trust
Dr Tom McCarthy	Western Health and Social Care Trust
Dr Mary McDaid	Western Health and Social Care Trust

The Chairperson (Mr Gildernew): I welcome, by StarLeaf, from the Western Trust Dr Tom McCarthy, who is a consultant clinical psychologist. Can you hear me OK, Tom?

Dr Tom McCarthy (Western Health and Social Care Trust): Yes, I can indeed.

The Chairperson (Mr Gildernew): Thank you.

I welcome Dr Mary McDaid, consultant clinical psychologist. Can you hear me OK, Mary?

Dr Mary McDaid (Western Health and Social Care Trust): Yes, I can.

The Chairperson (Mr Gildernew): Thank you.

From the Southern Trust, we have Denise Carroll, head of service for child and adolescent mental health services (CAMHS). Can you hear me, Denise?

Ms Denise Carroll (Southern Health and Social Care Trust): Yes, I can indeed.

The Chairperson (Mr Gildernew): We also have Dr Liz McMonagle, who is clinical lead in adult psychology services. Can you hear us, Liz?

Dr Liz McMonagle (Southern Health and Social Care Trust): Yes. Good morning.

The Chairperson (Mr Gildernew): We are joined from the South Eastern Trust by Dr Mandy Irvine, who is assistant director of psychological services. Can you hear me OK, Mandy?

Dr Mandy Irvine (South Eastern Health and Social Care Trust): I can, yes. Thank you.

The Chairperson (Mr Gildernew): We also have Julie Kilpatrick, who is assistant director of children and young people's healthcare in the South Eastern Trust. Can you hear me, Julie?

Ms Julie Kilpatrick (South Eastern Health and Social Care Trust): I can, yes. Good morning, everyone.

The Chairperson (Mr Gildernew): Thank you. From the Northern Trust, we are joined by Ciara McKillop, who is assistant director of child health development and emotional well-being. Can you hear me OK, Ciara?

Ms Ciara McKillop (Northern Health and Social Care Trust): I can, thank you. Good morning, everyone.

The Chairperson (Mr Gildernew): Thank you.

We have Jayne Colville, who is improvement coordinator in the autism spectrum disorder service. Can you hear me, Jayne?

Ms Jayne Colville (Northern Health and Social Care Trust): I can indeed. Good morning, everyone.

The Chairperson (Mr Gildernew): Morning, Jayne.

Last but not least, from Belfast Trust, we have Moira Kearney, who is interim director for mental health and intellectual disability. Can you hear me, Moira?

Ms Moira Kearney (Belfast Health and Social Care Trust): Yes, I can.

The Chairperson (Mr Gildernew): Thank you, Moira.

We have Dr Sarah Meekin, who is head of psychological services. Can you hear me, Sarah?

Dr Sarah Meekin (Belfast Health and Social Care Trust): Yes, I can.

The Chairperson (Mr Gildernew): Thank you. The panel is very extensive and experienced. We are delighted to have that level of expertise at our evidence session this morning. However, it will require careful time management. If members know who they wish to direct their question towards, I ask them to do so. If they do not, hopefully, a member of the panel will indicate that they will take the question. I am conscious that we have all the trusts here and that there are huge disparities across the trusts, but I ask people to give only a principal answer and then indicate if information needs to be added. If panel members indicate with the raised hand function, I will try to manage the meeting in that way, but it could be difficult. I ask everyone to be as succinct as possible in their questions, answers and opening remarks. In the event that we do not get to some members' questions, we can facilitate that via the Clerk and put those questions in writing to the trusts, and we can then disseminate the answers back. Indeed, if answers are complex, long or would benefit from a written response, panel members should indicate that in order to facilitate the time pressures in the session, given the scale of the issues and contributions we will get.

Having rattled through all that, I thank you all and very much welcome you to the Committee this morning. Tá fáilte romhaibh uilig. I ask panel members to, if possible, use headsets and ensure that they are on mute when they are not speaking. Not doing so can have a detrimental impact on the sound.

I will ask for very short opening remarks from each of the trusts. I will bring you in in the same order in which I introduced you, so I will go back to Tom from the Western Trust. Tom, will you or Mary make some brief remarks on behalf of the Western Trust, please?

Dr McCarthy: I think there was a generic opening remark that someone wanted to make. Sarah, do you want to read that out?

Dr Meekin: Yes. If you are happy, we agreed a general statement on behalf of us all that can then be followed up with each trust as needed. I have been chosen to give that generic statement.

The Chairperson (Mr Gildernew): OK. Go ahead, Sarah.

Dr Meekin: As you said, given the number of people who are here, discussions on autism can very quickly reflect the complexity of the diagnosis and the wide spectrum of need that individuals with an autism diagnosis have. Dr Stephen Shore, who is a college professor with autism, said:

"If you've met one person with autism, you've met one person with autism."

It is important to keep that quote in mind. We know that there is a lot of diversity in the need for support in daily life, both in personal needs and the availability of family and community support. We have the coexistence of other challenges, such as mental health issues or learning disability, which can add complexity to service delivery. We also need to keep in mind that the lifelong nature of autism requires a lifespan approach.

There is really good collaborative working and sharing of information across the trusts. That is facilitated by the local coordinator roles, which are invaluable, and that working would be further facilitated by a regional coordinator appointment. All the trusts have a multidisciplinary team (MDT) model of delivery and follow National Institute for Health and Care Excellence (NICE) guidelines on autism assessment and intervention. The recent joint working has been very well demonstrated over COVID, given the challenges of delivering diagnostic assessments, and a task and finish group was gathered to review options and make proposals on progressing a safe and standardised regional return to diagnostic appointments, which has been achieved.

I will focus on children's services and then adult services, if that is OK. Children's services have predominantly received the focus and the investment. They are fortunate to be driven by strong parental and familial advocacy and by the challenges that are experienced in an increasingly pressured education system. Meeting children's increasing needs in busy classrooms has also increased the profile of referrals. Work is ongoing to promote working between Education and Health. Those relationships have become much more collaborative over the years, but work continues on developing better integration. There are links between the board and the Education Authority (EA), and, at local level, we have very good working relationships between our educational psychology colleagues and autism services. There is also educational representation on local autism forum steering groups.

While there has been investment in children's services over the last 10 years, the demand continues to far outstrip the capacity. That remains a significant challenge. To give an example, Belfast Trust has had an average increase of 70% from the baseline in its referrals, year-on-year, over the last four years. That has resulted in a cumulative waiting list tail every year, in spite of often delivering above the funded assessments. The capacity challenges include funding, workforce availability and development. There is a challenge in the need to deliver diagnostic assessments while providing ongoing support and intervention.

Working collaboratively with our colleagues in the third sector organisations, including the private sector, is a strategy to bridge the gaps in service delivery. However, we note that those relationships will not meet demand. The trusts have ongoing and developing contracts with colleagues in the third sector, including private practice, for diagnostic and intervention work.

There is no doubt that COVID has had a significant impact, particularly on our ability to deliver diagnostics, and that can be seen in our increased waiting times, which were already challenging. However, we note that we have invested our time in developing and delivering earlier intervention and specific autism intervention supports, and that is reflected in the reduced waiting times for interventions. We also note that we have continued to complete assessments and support families throughout the pandemic, and we have embraced new and innovative ways of working. The

opportunities to access support through online resources, such as virtual Zoom workshops and virtual one-to-one appointments, have been very well-received by young people and families. However, at the end of August 2021, 5,642 children were awaiting assessment, with nearly 20% waiting over a year. By the end of September 2021, there were 718 children awaiting intervention, although the numbers that waited over 13 weeks was significantly reduced due to the move of additional resources towards that service over the COVID period.

As trusts, we really welcome the development of the emotional health and well-being framework, which has a focus on early intervention. Again, we note that a lack of any significant funding will impact delivery and the ability to produce effective change. We note that the framework is not about autism but acknowledges that, in early childhood, children can present with delays and challenges in key developmental areas, and early intervention at that time has been shown to reduce later morbidity. In order to enable progression to more helpful developmental trajectories, a focus on that may help reduce some of the autism referrals in the early years and ensure that children and families are still getting the support that they need. We note that autism-specific early intervention needs to ensure that there is adequate funding for autism services. That will give better support for not only diagnostic assessments but ongoing and repeated inputs over the lifespan of children, young people and their families during the different transitions and changes they progress through.

Adult services are significantly and severely challenged. They have no targets and have not received any degree of significant investment in services. I note that we have written the word "EVER" in capitals. There are not really the same strategic drivers or loud voices for that population, which struggles to advocate for itself. There is a percentage of adults with autism who will have comorbid learning disabilities and/or a mental health need. They can access support from those programmes of care. However, other people with autism who do not meet the threshold for inclusion in those programmes can experience significant difficulties with delays in access to support, and that can have a knock-on effect on their mental health. They can have difficulties sustaining employment and a history of fractured relationships, which can have an impact on emotional well-being. The third sector options are, again, less available for adults.

Adult autism services have experienced a significant increase in demand in recent years, including demands from young people transitioning from children's services and an increase in referrals for adults who have not had an opportunity to access diagnostic assessment in childhood. For example, the South Eastern Trust has a predicted 42% increase in referrals for 2021-22 in comparison with the baseline year of 2019. The Belfast Trust has, year-on-year, a 300% demand, which is in excess of the capacity for referrals received versus its diagnostic ability. Again, that results in increased waiting lists tails every year.

There are around 1,474 adults awaiting a diagnostic assessment and 206 awaiting an intervention. Those are significant waits, with the waiting time for a diagnostic assessment being an average of three years and a year for an intervention. We had a regional workshop for adult autism in September 2019 where a broad range of adult needs was discussed. It was noted that at least 70% of adults experience at least one mental health condition. They also have significantly high rates of physical difficulties, including cardio-related difficulties, epilepsy and diabetes and a reduced life expectancy of around 16 years, which results in significant inequality. They have high rates of unemployment and economic inactivity, as well as high housing needs and issues relating to poverty. With all that in mind, we are keen to ensure that autism does not continue to be seen as a health problem. The key message in the Autism Act (Northern Ireland) 2011 was that autism is everyone's business, but, to date, it feels that all the emphasis and challenge is on and in health. Diagnoses are often sought in order to gain support for learning and achievement in educational settings or to support employability. Thus, the role of employers and other governing bodies in supporting key normative life goals, such as jobs, leisure and housing, needs to be more focused and upheld.

We appreciate the time that you have taken to hear the statement.

The Chairperson (Mr Gildernew): Thank you, Dr Meekin. Responses on the Bill across the board indicate that significant resource would be required for an early intervention service. Is that something that you have been working on? What resource would be required for that early intervention service? I will go to Tom, from the Western Trust, first. If no other order is indicated, I will work in the order that I have on my list. Tom, what is your opinion on the early intervention service?

Dr McCarthy: I work in adult services, and Mary can maybe jump in to talk about children's services. The question seems to be focused on children's services, although I appreciate that adults with ASD also require early intervention. They may have waited for a long time to get an assessment and

diagnosis, so the interventions that go with those are needed and timely at that stage. I am unable to give you today the cost that you are asking for. If needs be, I can update the Clerk with an idea about how required funding for early intervention for adult services would need to be approached or looked at.

The Chairperson (Mr Gildernew): It would be useful if each of the trusts came back in writing with their assessment of what would be required rather than speaking individually now. That brings me to 'Being Awesome — Autism and Adulthood 2021', a recent conference report from the Southern Trust. I commend the trust for that, but I am sure you will agree that it shows some worrying figures. It shows dissatisfaction at around 79% or 80% in some cases and some other worrying elements. Some 79% are dissatisfied with access to information, which is a fairly basic requirement, and 79% are dissatisfied with the provision of services. What comment have you on what the report tells you, what improvements are needed and how it would link with the elements of the Bill that we are scrutinising? I will direct that at the Southern Trust, please.

Ms D Carroll: There is a huge focus in the Southern Trust's autism services on patient and public involvement. We have our parenting group that we work with very proactively, and we involve our group of young people across the trust in absolutely everything that we do. I appreciate the responses in the 'Being Awesome' report that show that 79% of people are dissatisfied. In order to address those figures, I will say that it is about working with our young people, adults and families to ensure that there is satisfaction across the board. At the start of the COVID pandemic, resources were pushed into online resources and ensuring that we continued to meet the needs and demands of our young people and families.

We have a monthly drop-in service for families, which is designed by them, and we strive to do that in conjunction with them. With monthly drop-ins, we have 200 logins each month, and that is designed by the families. That is 200 logins, not 200 people. We will continue to strive to work with our families and young people in order to get full involvement.

As Sarah — Dr Meekin — touched on at the start, that is easier with our children and families because there is huge advocacy support for them. With our adults, it is much harder. They do not have that strong advocate or that strong voice behind them, so it is harder to reach out to them and get them on board with our working together partnership. We work very proactively with our parents' group, Acorns for Autism, and we do a lot of work and have done a lot of joint ventures with it. One example of that is the walled garden, which is accessible to members of the public, including children and young people and, indeed, adults. They can access it at the weekend, and it is a safe environment for those who have a diagnosis or are awaiting a diagnosis of autism in the Southern Trust area. Lots of co-work is being done.

Dr McMonagle: I will go back to the comment that Sarah made at the beginning. The world of service for adults is incredibly challenging and needs dedicated attention. Chair, I very much liked your question about intervention. We would go back a step and consider the importance of adults being able to get timely diagnosis in order to access support and intervention. One thing that is fundamentally important in that is that they can access a spectrum of supports. As mentioned in Sarah's presentation, one of the challenges at the moment is that supports are often predicated on, for example, also having a coexisting learning disability in adulthood or a mental health presentation. There is a proportion of people who are not able to access services and supports if they do not fall within that remit. We are very mindful of that.

The Chairperson (Mr Gildernew): I will go to Paula first.

Ms Bradshaw: Thank you, Chair. I wanted to make sure that I got in early today, because I did not want it to seem like I am not interested. It is just that sometimes my questions are asked before I get in.

I have two questions about one of the submissions. I think that the Belfast Trust talked about the cost and time implications of providing information to the autism reviewer. Given technology now, is there no way that systems can be set up so that it would be quite simple to extrapolate the relevant information for the autism reviewer?

The second question is about the response around the measurable targets to assess the effectiveness of autism services. Is there a way in which you are measuring the negative impact of assessments not

being carried out and the appropriate care not being put in place, such as, for example, a deterioration in the mental health of an individual patient?

The Chairperson (Mr Gildernew): Will someone indicate that they are picking that question up?
[Pause.]

Ms Bradshaw: Sorry, that was actually to the Western Trust.

Dr McDaid: Good morning. Hi. I will pick it up.

I will go to your first question, Paula, which was about the information that the reviewer might request. Yes, we deal a lot with our colleagues in the information service in the Western Trust and produce a significant amount of data, which is really helpful for how we manage our services. We certainly want to be thorough and comprehensive in producing whatever data would be required for the reviewer, and, in order to do that, additional staffing may be required. We had just one issue or query about that. It was really just to make sure that we would be efficient and thorough in the provision of data.

However, you are absolutely right: information systems develop all the time, and we have comprehensive information systems in the Western Trust and across the region so, perhaps, over time, provision of that data may become more straightforward.

Ms Bradshaw: My second question was about the impact on the patient where services are delayed. Is that being measured anywhere? Maybe it is measured in academia, but, in the trusts, is anybody picking that up with the families?

Dr McDaid: In the Western Trust, we have a helpline in place for families that are on the waiting list. We answer many calls on a daily basis, as I know colleagues across the region do. Every day we hear about the impact on children, families and carers. We do our very best to implement some brief services at that point. We are also in the process of developing an early-intervention service.

The difficulty we face is that our referral rate has increased; it has tripled since 2010. As a consequence, our capacity to see the children efficiently is much reduced. We have capacity for approximately 420 assessments, and, in 2019, we received about 700 referrals. Therein lies the problem. We can see only a certain number of children per year. I heard some of the witnesses speak in previous sessions, and I found them incredibly interesting, but they were also talking about making sure that we make effective, thorough and comprehensive assessments in line with National Institute for Health and Care Excellence guidelines. We need to do them properly and get the right diagnosis to the children. We are very aware of the impact on patients, but we have a difficulty with capacity at present.

Ms Ní Chuilín: Thank you, panel. It is apparent that, without the involvement of parents and the community and voluntary sector, the costs to Health and Social Care (HSC) would be much greater. However, constant inequalities are faced by children and adults with autism. First, what opportunities does the Bill give to address those inequalities? Secondly, what are the equality implications in a situation where there is a three-year waiting list for children and a five-year one for adults? Thirdly, reference was made to the independent sector as a partner. I do not get the fact that ability to pay for diagnosis is being missed. I do not want to pick anybody up wrongly, but what role has the independent sector? Would it not make much more financial sense to invest in health and social care staff to make these diagnoses? At the minute, we have an additional inequalities on the basis of ability to pay. Those are my questions.

Dr Meekin: I am happy to pick up on your comments on the independent sector. The reference to the independent sector was in the context where the trust would contact the independent sector to augment our diagnostic capabilities. It does not produce inequality in providing access. We are not suggesting that people pay for their own diagnoses; rather, it is a way of augmenting the trust's capacity to provide assessments. We can do that sometimes when, for example, we have a vacant post and are in the process of recruitment or if we have someone on maternity leave and have difficulty getting temporary backfill. It is a way of making sure that we make the best use of the available funding. In the short term, we purchase additional sessional input. However, where we have long-term funding, we always look to recruit permanently to those posts. Due to workforce issues, there can be a delay in recruitment, or we might have somebody on maternity leave, so there would be no permanent post to advertise. That is what the reference to the independent sector was in connection to.

The Chairperson (Mr Gildernew): Thank you. Could a member of the panel pick up on the other questions, please?

Dr Irvine: Chair, perhaps I could comment on the inequality between adult and child services and waiting times.

The Chairperson (Mr Gildernew): Thank you.

Dr Irvine: As the question noted, there is a significant disparity between waiting an average of three years for a child assessment and five years for an adult assessment, both of which are completely unacceptable from a service-user and family perspective. The reason for that disparity, however, is that the two services are funded separately. They are commissioned by two different departments within the board, so there is no consistent requirement for the services to have similar waiting times. I also note that there is a ministerial target for waiting time for children's services but not for adult services. I feel that that has been to the detriment of adults whereby, without a ministerial target, there has been significant drift in waiting times and a lack of focus thereon. Thank you, Chair.

The Chairperson (Mr Gildernew): What was your final question, Carál? I will ask somebody to pick up on it.

Ms Ní Chuilín: It was about people's ability to pay when they have to go to the independent sector to get diagnoses either for their children or their adult children. What are we going to do to reduce those inequalities for families?

The Chairperson (Mr Gildernew): I see Sarah indicating to come in. The other part of that was about the desirability of having core health and social care staff, rather than outsourcing. Go ahead, Sarah.

Dr Meekin: Hopefully, I have answered the question of why we, as a trust, go to the independent sector. The reality is that there are families that pay for their own assessment. We have all discussed that over time. At one point, the trusts did not accept independent assessments. However, that felt almost as if we were creating our own challenges with waits. At least allowing that moves some people off our waiting lists and allows us to progress with greater ease. Not accepting those assessments was an inequality in itself, so we made that decision. Those assessments are only accepted, however, if they are carried out in accordance with NICE guidelines.

We are trying to address inequalities at all levels. Ultimately, we do not have the capacity to meet demand, which is the only way by which the inequality would be fully addressed.

The Chairperson (Mr Gildernew): Thank you. I will pick up on that point. In your opinion, Sarah, are measures being put in place to develop that capacity rather than simply outsourcing?

Dr Meekin: We have a plan to recruit to our vacant posts, and we are progressing that. As we outsource, we build capacity internally, which means that people get their assessments more quickly. I think that I speak for everyone when I say that, where there are vacancies, we move to progress to full recruitment. Even when we have full recruitment, however, we do not have the capacity to meet the demand at our doors. Therefore, there continue to be long waits.

The point that I was trying to make earlier is that even outsourcing — using our community colleagues and any private-sector availability — does not fully meet the full demand of the waiting lists.

Mrs Erskine: Thank you to the panel. I have two questions. The first is about the Western Trust. I believe that, in its written evidence, it supported the placement of an autism reviewer within the existing structures. Can someone comment on how the independence and scrutiny roles could be protected in that scenario, as well as the cross-departmental remit of the role?

The Western Trust states that resource does not meet demand for early intervention. We have talked about the importance of that, with studies showing that working with parents and young children can offset those numbers. What does early intervention look like? How quickly would we like to see early intervention happening? What impediments are there to it? Is workforce the main issue?

Dr McDaid: I am happy to pick up on the query about early intervention, given that we made that response in the document that we submitted. As clinicians, we believe that early intervention is critical. There are many stages at which early intervention is important. Early intervention is important at the

very first time that difficulties emerge in a child, and that may be pre-diagnosis. Early, and timely, intervention is important once a diagnosis has been made for families to get used to a diagnosis and to adjust to it.

There is another stage at which early intervention is really important: as a child is developing the diagnosis of ASD, they may meet many new challenges along the way and may require additional support. They might have received their diagnosis at the age of four, but they might present to services at the age of 14, facing new transition and new challenges. At that stage, they also need early intervention, and by that I mean timely intervention. Early intervention is also specialist because it should be provided to children in an individualised way, based on their presenting need. It often requires specialist formulation to ensure that we get the right intervention for a particular child and a particular family.

You will have gathered, from what I am saying, that that will require a substantial resource, given the number of children coming to us at the pre-diagnostic stage, the number of children we have with a diagnosis, and the number of children who return to our service as they develop over time. We have four members of staff available to provide early intervention, and, based on our capacity analysis, we feel that we need a lot more additional staff to provide that intervention. We have close collaborative working arrangements with our voluntary and community sector, and it also supports us very well in providing early intervention. However, we need consistent recurring funding to stabilise the service and to make sure that early intervention can occur for families across the age range.

The Chairperson (Mr Gildernew): Thank you. Deborah, was there another element to your question?

Mrs Erskine: Dr McDaid mentioned the trust's having four staff for early intervention. How many more staff do you think you will require? I asked you to comment on the independent scrutiny role of the autism reviewer. The trust said that it might support its being within its existing structures.

Dr McDaid: Deborah, I would appreciate some time to come back with a more developed answer on the cost and the additional staff required rather than thinking on the spot right now, if that is OK.

On the reviewer, when we had our discussions in the trust, we thought that a lot of reviews are ongoing on ASD, and we present a lot of data to the Department and to the Health and Social Care Board. That data gets reviewed and analysed, so we wondered whether the current review arrangements could perhaps fulfil that function. There are also other reviews across children's services, such as by the Children's Commissioner and by the ombudsman. I personally do not have strong opinions on it, but, in an attempt to prioritise clinical services, we wondered whether it could be accommodated within existing structures.

Ms Flynn: Thank you, panel. First and foremost, I have a question that is for each of the trusts. I am conscious of the limitations on time, but some of the presentations have been very light on detail and on commitments. One of the doctors mentioned the difficulty that you are having with capacity, which is a genuine concern for your capabilities, waiting lists and the delays in treating people. Should the workforce be an issue addressed in the Bill or the strategy? Is there anything more specific that we can put in the Bill to assist you in the work that you are doing?

I have some questions for witnesses from the Belfast Trust — Moira and Dr Meekin — specifically. Will you expand on the comments in your written submission on the confusion that exists and the need for further clarity on early intervention on autism, as contained in the children's health and emotional well-being framework?

Dr Meekin, going back to the private diagnoses and the referrals that are made to your trust, the collection of data in that area has been very poor. Why is the data on the number of private referrals coming into the trust and the number accepted not recorded? How many are we talking about? We are discussing health inequalities: some people pay to get a diagnosis more quickly whereas others can wait for years on the list. That is a massive health inequality, so will you elaborate on that?

The Chairperson (Mr Gildernew): Dr Meekin, your hand was already up, so I will go to you first to check whether you were looking in previously and then pick up on Órlaithí's questions.

Dr Meekin: Thank you, Órlaithí; your questions are really helpful and are related to the reason why my hand was up, namely the discussions on early intervention. One of the things that we commented on

was the importance of understanding the ask in early intervention. Dr McDaid has been very helpful in looking at the different types of early intervention and the different ways in which it can be delivered.

For any new Bill, we would need a much better understanding of the ask in early intervention, particularly if we are looking at costs, etc. Dr McDaid's point on early intervention is that it spans input into perinatal issues and early infancy right up until after a diagnosis has been made. The emotional health and well-being framework is focused not on autism but on the fact that children can present with challenges in their development from early stages and that support for that does not always require an assessment of autism. The aim is to move to a more needs-led basis for providing support and away from the diagnostically driven system that we have now.

That was our ask for the discussion on early intervention. It still is. Is the requirement about that early intervention framework, which is much broader and includes the role of our colleagues in health visiting and other aspects of children's service delivery, rather than just a focus on autism? Or are we looking at early intervention for someone who has a diagnosis of autism? Those are two different conversations that sometimes get a little bit mixed up, which can make it difficult to look at needs. So, clarity is required, particularly on any new amendments to the Bill, on what early intervention looks like and what the desired outcomes would be. That is an important aspect for us.

Data on private assessments is not part of the data set. I know that that is not really a robust enough answer. In all honesty, I am not sure how difficult it would be to go back to try to get that data. However, I can look at that. We can take that back into the trust to see whether we can, for our information, look at the kinds of the numbers that come in.

Ms Flynn: Dr Meekin, thanks very much. It would be much appreciated if you could take that back. We have all the other trusts on the call. Is there any learning on that that the trusts can share with one another? I am not sure whether the other trusts want to comment on whether they record private diagnoses and, if not, whether they would commit to, or look into, doing that? Thank you.

Dr McCarthy: For the adult service, we do not keep a record of private diagnoses. Such a record can be kept. I know that the figures are very small, so it would not be an issue to find them. Mary, do you want to comment on that from a children's service perspective?

Dr McDaid: From a children's service perspective, we have a very small contract, using non-recurring funding, with an independent provider. We record the number of children whom we send in that direction. What we do not record is the number of self-funded assessments that are completed, although we certainly have no issue with recording them.

Ms D Carroll: From a children's service perspective, we do not currently record that. We record private assessments into the trust manually, as we do not have the systems to capture them electronically. We use electronic systems. As Dr Meekin said, it is not part of the data set. Although the numbers are small, we have begun to look at them and take them into account. Looking back to see how many we have accepted into the trust would involve a manual trawl, and, given the numbers, teasing out the difference between a trust diagnosis and a private diagnosis would involve significant work.

Dr McMonagle: We do not capture that on the adult side. We have developed criteria that look at whether diagnoses meet professional guidelines and NICE guidelines. It is not a significant number, so we certainly could capture that data. We do not see a significant number of private diagnoses coming into adult services.

Dr Irvine: As mentioned by the trusts, we do not have a high volume of private assessments. The number certainly can be captured. It could be added to the monthly data set that is routinely completed and returned to the board so that that information can be accessed.

There are two issues to note. The first is the financial inequality between individuals who can afford private assessment and those who cannot. There is further inequality insofar as, if someone pays for a private assessment, they are often guaranteed a confirmatory diagnosis. The trust has focused on ensuring the quality of those assessments, as mentioned.

From an adult autism perspective, many people may choose to pay for a private assessment and use that information to access benefits or additional supports in employment etc but not to access trust services, and we have no way of capturing that data.

Ms Kilpatrick: As for children's services in the South Eastern Trust, we do not formally record that. We know that the numbers are low, so it would be easy to trawl through them to capture the data. We would be happy to do that.

Ms McKillop: Like the other trusts, we do not routinely record private diagnoses. It is a small number. Those in the independent sector are largely trust staff who work additional hours. In the Northern Trust, we have tried to increase capacity by using overtime when we have had additional funding or small pots of non-recurrent money.

Ms Colville: Like the other trusts, we do not routinely collect that data. Again, like the other trusts, the numbers are low, so it is something that can be picked up on.

The Chairperson (Mr Gildernew): We have heard from Sarah on that point. Moira, do you want to pick up on that on behalf of the Belfast Trust?

Ms Kearney: I will continue in the same vein about their being easy to add. We are happy to add them on.

Ms Flynn: I thank the trusts for all that feedback. It is helpful, given the context of the conversation that we are having about young people, older people and families on waiting lists, as all of them are under extreme pressure. It is good to hear that feedback and for the public to have that information. It is also a positive that, although the data sets and systems that you have in place do not allow for gathering some of the data, it is straightforward and easy enough to do so. It would be much appreciated if you could feed the data back to the Committee.

Ms McKillop: There is a discussion to be had about inequality, but it is important that we do not exclude any children from any service because they do not have a diagnosis and that, when we offer an intervention to children, they do not need a diagnosis in order to access it. That is important to note as well.

The Chairperson (Mr Gildernew): Yes. I suppose, however, that the other side of that particular coin is how to know the correct services or the range of services that may be required if you do not have the information.

The other thing that strikes me from that question is that you all say that the number is very small but that you do not know what it is. In that sense, I do not understand how you can know that it is so small, but it is clearly significant, and it has been reported as being as such across the North. It also has a significant impact on those who are caught up in it.

In previous Committee correspondence, the Minister agreed to look at the issue. I am a bit surprised. If it is a question of adding it to the data set, why has that not been done? Some of you have committed to doing that, and that is appropriate, but, in every trust, we need to iron out the postcode inequalities in various areas. What does not get measured does not get done. It is as simple as that. If we are still not measuring it after it was raised by the Committee quite some time ago, I am concerned about that. I need to move on, but we want you to come back to us on what is being done to address the issue.

Mr McGrath: We are getting towards the end of the session, but I want to ask the panel for its perspective on this point. We have 10 people presenting, nine of whom are female and one of whom is male. Is there a shortage of males working in the sector? If so, does that have an impact, given that, I am sure, a lot of young men and older males will be diagnosed? What might be done to try to attract people into the sector?

When it comes to improving the service, does anyone have a good example of something that they have done that has helped get a quicker response time? Are there initiatives out there that can be shared?

The Chairperson (Mr Gildernew): Who wants to pick up on that?

Dr McCarthy: I will, given that I am the only male here. I do not know whether being the only male here today is reflective of all the teams. I do not know about all the teams, but there does seem to be a higher number of females. I am unsure whether that has an impact on the services provided. There

seems to be more of a bent for males to get a diagnosis of autism than females, and there is consideration and concern about females getting a diagnosis. Having more females in services might therefore assist with that issue.

I am not too sure how much the issue of gender impacts on the overall provision of service. I do not think that it would have a lot of impact, but I understand, and this happens to me as a male, that, sometimes, females want to work with females and, sometimes, they want to work with males. It is good to have a balance between services, but I am unsure how much it impacts fully on the service that is provided.

Mr Chambers: I have two questions for the South Eastern Trust representatives. First, do you consider investment in autism services over the years to have kept pace with the need, as evidenced in the Department of Health's annual prevalence report?

Secondly, I note the particular emphasis in your written evidence on regional coordination. Do you accept that that need for coordination extends to the need for independent scrutiny and the commissioning of, say, practice-based research to problem-solve current challenges?

Ms Kilpatrick: Thank you for your question, Alan. The funding has definitely not kept pace. We have seen significant increases not just in the number of referrals of children to autism services but in the complexity of those children. We work in the South Eastern Trust as a large emotional health and well-being service. We have a single point of entry, which is multidisciplinary. The team sits twice a week. Each week, we have between 60 and 70 referrals on each of those days, and we have developed complex pathways. The multidisciplinary team sits and looks at each of the referrals and decides, based on the information provided, to which pathway each of those children needs to go. We therefore have significant data and an ability to track the information that comes in and what happens with those children during their journey.

We absolutely could do with more and more resource to meet capacity. You talk about early intervention. We stepped out a number of years ago and built up a partnership with Barnardo's on ABC PIP — the Parent Infant Partnership attachment, bonding and communication service — which is around infant mental health. It looks at early intervention and, hopefully, at preventing those children coming into our services later and getting a late diagnosis. We have a lot of ideas about how we can extend and expand our services, but we require resource to do that.

Mandy, I do not know whether you want to answer the second part.

Dr Irvine: I will comment on the adult autism side. The trust welcomed the investment from the board approximately two years ago for an additional one and a half staff in the adult autism service, which has given us a total staffing complement of about three and a half staff for the whole trust for the delivery of diagnoses and intervention. We have estimated that we have capacity for approximately 50% of referrals to be seen year-on-year for diagnostic assessment. That results in an accumulative waiting list for people to be seen.

The trust has been very attentive in trying to increase our capacity to deliver work through the delivery of group-based programmes in collaboration with places such as the Belfast Recovery College, so we are connecting and collaborating with existing trust services to try to increase access for adults. The capacity to deliver the care, as well as the demand for services, is not matched by the funding that is available, however.

Mrs Cameron: Thank you, panel, for your attendance. Your time is very much appreciated. I know how busy you all are. On the Northern Trust response, I very much welcome the positive comments in support of increased transparency involving measurable targets and tracked autism service funding. Does the trust also see merit in the independent evaluation, scrutiny and coordination of practice-based research in problem-solving issues that relate to regional consistency in service delivery in the form of an autism reviewer?

The Chairperson (Mr Gildernew): Does any member of the panel wish to pick up on Pam's question about the reviewer?

Ms Colville: Thank you for the question. A bit like in some of the other trusts, consideration will be given to existing structures. Mary mentioned the reviewer, and we would be keen to work with anyone,

but looking at existing structures — some of the trusts mentioned the reporting mechanisms that there are — would be our *[Inaudible owing to poor sound quality.]*

Dr Irvine: Regarding the international research element and looking at the evidence base, there is a concern, as the panel is, I am sure, aware, that the prevalence rate reported for Northern Ireland is substantially higher than that in other parts of the UK. There would be value in investing in understanding the multiple factors that result in that increased prevalence rate for our part of the United Kingdom. Some research investment and focus on that would have important public health and service experience impacts for people diagnosed with autism.

Dr Meekin: I agree with Mandy that it is important to look at the research aspect and at Northern Ireland experiences. My other comment on a reviewer is that, as a health system, we provide a significant amount of information. Collectively, we share information with one another and through regional coordination. It would be helpful to ensure that any reviewer function had the breadth of the 2011 Act in view, looking at the wider issues, such as housing, employment and leisure opportunities and that aspect of autism-friendly living, as well as the issues of diagnosis and intervention. A wider lens would benefit people with autism by reducing the stresses that they experience in daily living and by giving them wider opportunities that would improve issues such as mental health.

The Chairperson (Mr Gildernew): Thank you, panel, for your time and contribution. With the greatest respect, however, I am, in a sense, disappointed. It would have been great to hear from you, "Here is how the Bill could add to the picture", or, even better, "Elements of the Bill are not needed, because we are doing a, b and c". We expect to hear from the sector and from families and individuals a lot of the problems and issues, but, when we talk to the trusts and the Department, I would like to hear more about the solutions, to be honest. I do not get an overwhelming sense of urgency about improvements. I recognise that you are all under tremendous pressure and that there are fast-rising demands. I know that some of these comments and questions are just as appropriate for the Department, but I did not get a strong sense that the trusts are working on a set of solutions or that workforce planning is taking into account how we are going to meet current needs, let alone the rise in demand that you all have identified and that, we all know, exists. A lot of work has still to be done on that. The Bill is useful for focusing on and drawing out that work, but we need to move from a position in which we outline the problems to one in which we say, "Here is what we suggest as part of the solution", or, indeed, "Here is the resource that is required", so that we can then work back from there. If we do not measure the right things, however, it is impossible to plan for how to address them.

I thank you all. There is a significant amount of work to be done on the Bill, but this meeting has been useful for focus. As we all know, autism has a huge impact out in the community. For now, I wish every one of you well and thank you for your attendance at the Committee. I wish you all the best in the time ahead. Thank you.