

DÁIL ÉIREANN

AN CHOISTE COMHAIRLIÚCHÁN POIBLÍ AN TSEANAID

SEANAD PUBLIC CONSULTATION COMMITTEE

Déardaoin, 29 Meitheamh 2017

Thursday, 29 June 2017

Tháinig an Roghchoiste le chéile ag 10 a.m.

The Select Committee met at 10 a.m.

Comhaltaí a bhí i láthair / Members present:

Seanadóirí / Senators	Seanadóirí / Senators
Jerry Buttimer,	Joan Freeman,
Maria Byrne,	Colette Kelleher,
Martin Conway,	Pádraig Ó Céidigh.
Máire Devine.	

I láthair / In attendance: Senators Paul Daly, Frank Feighan, Grace O’Sullivan, Niall Ó Donnghaile and Keith Swanick.

Seanadóir / Senator Paul Coghlan sa Chathaoir / in the Chair.

Children's Mental Health Services: Discussion

Chairman: I am honoured to open the public hearings of the Seanad Public Consultation Committee on children's mental health services in Ireland. These meetings are the second part of a process which began in April with a public invitation to make written submissions to the committee. On behalf of the committee, I thank all those who sent submissions to it, particularly users of the service, as it can be a distressing and difficult experience for families seeking mental health services. Through these public hearings, spread over two days, we will hear from all facets of the debate in the delivery of child and adolescent mental health services. Through sharing these experiences, the witnesses will set out the reality of those in need of mental health services, and those providing these services as well as from the policy makers. The committee hopes that through this public consultation initiative, we can first, highlight and provide details of the present situation whereby children are being placed into adult psychiatric units; second, analyse the effect on providers of primary and secondary care who seek out of hours and weekend care and on children and families in distress; third, discuss the waiting list for initial assessment under the Child and Adolescent Mental Health Service, CAMHS, by reference to different CAMHS catchments; fourth, identify reasons for unsustainable waiting lists for mental health services including staffing shortfalls in multidisciplinary primary care centres and the role of child psychiatrists under the Mental Health Act 2001 and the reliance on assessments being approved by child psychiatrists; fifth, look at best practice and the most successful models in mental healthcare for children and adolescents; and sixth, create proposals to decrease waiting lists and streamline inpatient care. Following our two public hearings, a draft report will be prepared for our committee by our rapporteur, Senator Joan Freeman. The committee will review the draft report and publish its final report as soon as possible thereafter.

Today's meeting will consist of two sessions. In the morning, we will hear from the families who are using the service and in the afternoon session, we will hear from advocacy groups and service providers. On behalf of the committee, I welcome the witnesses to this morning's session, Ms Lauren Keogh, Ms Paula Dalton, Ms Louise Walsh, Ms Sinéad McGee and Ms Martina Kelly. They are most welcome and we thank them for engaging with the committee in its consideration of this most important and sensitive topic.

Before we begin, I must advise that by virtue of 17(2)(l) of the Defamation Act 2009 witnesses are protected by absolute privilege in respect of their evidence to the committee. If they are directed by the committee to cease giving evidence on a particular matter and they continue to do so, they are entitled thereafter only to a qualified privilege in respect of their evidence. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given and they are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against a Member of either House, a person outside the House or an official by name or in such a way as to make him or her identifiable. Any opening statements that have been submitted to the committee will be published on its website after the meeting.

I now invite Senator Joan Freeman to make some introductory remarks. I will then invite each witness to make a short presentation to the committee. When the presentations have finished, there will be time for questions and comments from the Senators and responses from the witnesses.

Senator Joan Freeman: Earlier, I sat among these women who are speaking to us this morning and the description that came to me immediately was that these are warriors of Ireland.

We are among five warriors. These are mothers who have travelled a journey with their children and have agreed to come here today to tell the public and the Government about the nature of their journey so far. I call them warriors because they have had to fight tooth and nail from the day their child was first diagnosed to where they are today. They are also warriors because they are speaking in public. They are all very nervous. Not only have they never spoken in this Chamber before, they have probably never spoken about their experiences publicly before and I very much appreciate them and their coming here today.

They wanted to take and show a photograph of their child so that members can see that this is a person we are talking about, not a number. I am asking the Chairman that we ensure that the cameras would not focus on the child because we need to make sure that this child is not stigmatised in any way. The witnesses want to show the people present that they are talking about a little boy or girl.

This public consultation day is about painting a picture. It is about painting a picture of what mental health services are like in Ireland but particularly what it is like for our children and their families. This is not about accusing anyone. It is not about accusing the Government, the CAMHS or the HSE; we are here to paint a picture. What we see or hear up to now are reports. There have been 12,000 reports on children and mental health services but now members are going to see and hear the real story about what it is like to live the experience of the services here in Ireland. This morning is about listening to these parents and this afternoon we will listen to what it is like for the service providers, those who are on the front line, to work in this area and with the resources available to them.

I thank the Chairman and everyone for coming here this morning. I am sorry there is not a bigger turnout. I know that Ms Kelly, for instance, has been up since 4 a.m. and travelled from Sligo, but I can assure her that I will continue to fight for her on this.

Chairman: I welcome the women once again and ask Ms Lauren Keogh to begin.

Ms Lauren Keogh: My name is Lauren and I live in Meath, falling under CHO 8. I had my daughter Zara when I was 16 years old. A lone parent, very young and vulnerable, my parents supported me to ensure that I finished school, went on to college and worked full time to ensure I could provide for Zara. I have since married David, Zara's stepfather, and we have another daughter together, Robin, who is five years old. Zara is 13 years old. She is a funny character who always seeks a smile from others. She has a diagnosis of autism spectrum disorder, borderline mild general learning disability, hereditary neuropathy with tendency to pressure palsies, HMPP, and more. As a result of her diagnosis, Zara is listed on both disability registers, the intellectual disability and autism register and the physical and sensory register. She adores animals and is involved in a charity called Olivia's Special Horses, therapeutic horse riding, for the past two years. The founder of this charity gave Zara her very own horse called Felim. Zara is obsessed with him.

Zara was quite young when she presented with challenges. When she was in junior infants she was referred to psychology in school for her behavioural issues. She took her shoes and socks off during class daily, she was defiant and refused to co-operate with staff, including the principal. She struggled with concentration, she could not differentiate between work and playtime, and I was regularly called to the school to collect her. There was a slight improvement after psychological intervention when demands were reduced and adaptations made but we would continue to have regular challenges. At six years old she developed a palsy in her right leg which lasted six months. Through the neurology department in Temple Street, she was di-

agnosed with HMPP, a physical disability affecting the nerves in her limbs. When Zara reached fifth class in school, she became very aware of her difficulties and compared herself to her peers daily. The school could not provide a NEPS assessment so we went privately at a cost of €600, choosing not to pay my mortgage. Zara had learning difficulties. The educational psychologist also had concerns around ADHD.

The school then referred us to the disability team for assessment of need. The purpose of the assessment of need is to assess the child's needs and what services are required. She was labelled with a physical disability and all other concerns were dismissed. I challenged this and was advised that the disability team had labelled my child as physically disabled and what more did I want. I felt physically sick. I gathered from that that the staff only wanted to tick a box and move on to the next case. I highlighted the educational psychologist's concerns of ADHD and asked how they could just dismiss the observations of the professionals. I was told they would look into it and call me back. Shortly after, I was told that the staff member dealing with Zara's assessment did not read the report submitted by the educational psychologist and that they would refer me to CAMHS after discovering this. I can only presume that the staff did not have time to read all the reports. Sickened I had that awful battle, I was glad that Zara was going to get the right service. "Thank God", I thought. Then I discovered that the waiting list was another 18 months.

After two months sitting on the 18 month waiting list for CAMHS Zara stopped eating and made regular comments about being fat. She also vocalised regular suicidal thoughts. Zara was ten years old. She needed supervision 24-7 so I had no choice but to leave work. The house needed to be cleared of anything with which she could harm herself. We hid the knives, medication, matches for candles and so forth. I chose not to pay my mortgage that month again and went for a private assessment. Expecting ADHD she was diagnosed on the autistic spectrum, which should have been identified initially in the assessment of need.

I went back to my GP and doctor on call, as I did not know where else to seek urgent help for her. The GP sent another referral to CAMHS outlining the seriousness of my concerns. Zara was seen within three weeks - that was May 2015 - and soon after was diagnosed with anorexia nervosa. CAMHS do not deal with disabilities so they would not provide psychology to address the root cause of anorexia. They also advised initially that they do not accept private diagnosis and they would only treat Zara as having HNPP. I asked them to treat Zara as Zara. I did not care about the label but needed help with the challenges she presented. Within a few weeks of thorough dealings with Zara for anorexia, CAMHS agreed with her private diagnosis of ASD. CAMHS referred her back to the disability team in October 2015 in respect of her ASD. They also diagnosed anxiety, sensory issues and difficulty managing emotional regulation. They provided a block of occupational therapy, OT, for this. Zara was discharged from CAMHS in November 2016 as she had beaten anorexia. That was a year and a half after starting with CAMH services.

However, Zara was still sitting idle on the waiting list for the disability team. It took more than 18 months on a waiting list to get back to the team that she first went to for an assessment of need, two and a half years after her initial referral for the assessment of need. Zara had her first psychology appointment on 13 June 2017 with the disability team.

There were many delays to Zara's treatment due to the current system. Under the Disability Act 2005, I was entitled to a service statement outlining Zara's needs and the services required within one month of Zara's assessment of need being completed, but the liaison officer who provides the service statement was on long-term sick leave. It took two years for me to receive

Zara's service statement. Her assessment of need was completed in February 2015 and I only received the statement in February 2017. During these two and a half years Zara had a great deal to deal with - multiple diagnoses, including the unnecessary battle with anorexia nervosa, three operations, becoming a wheelchair user, three school moves as well as her daily challenges. Zara is only now receiving the correct services, two and a half years later. We were fobbed from one waiting list to another at a cost to our daughter's mental and physical health.

As a parent of a child battling her way through the system I have been through much unnecessary stress. Thankfully for my children's sake, I am a dedicated mother with a supportive husband and I pulled together the mental strength to consistently fight my way through this journey. There is no support for parents going through the system. Nobody tells one anything about the supports available or even where to look for resources. Last year, I was prescribed Xanax to help me cope. However, this affected me physically and I struggled to function. I decided to do a part-time FETAC level 6 course privately and at another cost. I qualified as a special needs assistant purely to try and cope with the demands of my daughter's needs. I was always very driven and had many goals to continuously develop and progress in life, always pushing myself further. Now my goal is to get through the day. As a person diagnosed with high functioning autism too, this is extremely difficult to adapt to. Even more difficult to comprehend is the lack of support available to siblings. I expect Robin to have complex issues in the future caused by the impact of Zara's meltdown. Something as simple as the availability of a sibling coping skills group or a peer support programme would make a huge difference.

I understand funding is everything, but we are only kicking a can down the road. These issues must be dealt with while children are young to teach them the coping skills and to teach the parents and give them the tools to help their child. Otherwise there will be enormous demands on the services in their adult lives. I am aware the funding allocated is based on the figures on the disability register. If the staff had time to deal with each case adequately, the results and figures recorded on the register for funding would be factual. Other children are being missed and not listed on the disability register. Ours was one of those families. Zara's autism diagnosis was identified through the assessment of need. During the assessment my concerns were not listened to, I was made to feel like an inconvenience and then like a parent wanting a label. All I wanted was the correct support, fearing what was to come if I did not get Zara the help I knew she desperately needed.

While excuses are made by those who are accountable, they are choosing not to eliminate the waste within the system. We must ask questions. What are we trying to achieve? Is it working? A system with enormous waste resulting in life threatening effects on its clients is not fit for purpose. As a person who likes things to be productive, meaningful and efficient, I encountered a huge amount of waste within the system and items that add value to a service not being utilised, for example, staff not being replaced when on leave, reports not being read, fobbing children from one waiting list to another and so forth. With HSE staff under serious pressure to cope with the demands, it is no wonder many are out on leave and the turnover is huge. I fear the future. What do I do if the psychologist we waited so long for gets pregnant or becomes ill? She will not be replaced, and neither will my daughter if she succeeds the next time.

Ms Paula Dalton: I am in the CHO 5 area. I thank the committee for giving me the opportunity to speak about my son Rhys who is 13 years old. I will hold up his photograph to the members.

Rhys was born at 34 weeks gestation. He was very small and had to fight a great deal harder than other children to get home from hospital. I never felt such joy as on the day I held

my beautiful little boy in my arms. Rhys was diagnosed with high functioning autism when he was four years old. Even with this diagnosis, my son was a very happy, sociable little boy with family and close friends. Rhys was always a happy, energetic child who had a great love of learning about animals and different countries and their cultures. He taught himself basic French in a weekend when he was six years of age. He was extremely intelligent. He loves to go out with his friends and to have pizza at a youth club. He wants to be a boy who can do everything his friends can do.

In 2012, my son first showed signs of self-harming. He tried to cut himself with a butter knife. He also tried to stop eating. When asked why his reply was, "So I can die". My son was eight years old and he wanted to die. He said, "I want to close my eyes and they never open again, so I don't feel any more pain". For a parent, this was awful. I will never forget looking at him and wondering why and how this had happened and where my little happy boy had gone. As my son was diagnosed with autism we had access to the ASD team. We contacted the team and the team saw him and spoke with him. The team felt his needs had clearly gone beyond its area of expertise so it referred him to CAMHS. We waited 12 months for an appointment. At the appointment we met with the psychologist. She spoke with us and my son and said she would see us again. We were waiting six months for the next appointment. When we got there we had a different psychiatrist who asked us why we had turned up that day and why we were there. I had to show him my letter to prove we had an appointment. He did not know we were due to arrive there.

There were another few months of going back and forth and each time there was a different psychiatrist. This upset my son. As he was nervous he did not wish to speak to somebody he did not know. Then he was discharged. We did not know he was discharged. We found out six months later from our GP. We got no letter of discharge. In October 2016, my son attempted suicide. We took him to our GP who sent us to the emergency department. We were sitting in a waiting room full of other people for over four hours. Nobody had seen our son. Then a nurse came to tell us that we had to go to a different hospital two hours away as the hospital did not have a child psychiatrist to see our son. We went to the next hospital and the CAMHS team was wonderful. Its members calmed him down and spoke to us. They highlighted that they were extremely concerned for my son and said there was a CAMHS team in our hospital. It said it would fax our hospital and explain the urgency of the situation. It was hoped that we would be seen within the next few days. That did not happen. We waited three weeks for an appointment. It does not seem long, but when one's child is physically trying to hurt himself, is not sleeping, is hearing voices and is terrified, three weeks is a very long time to be dealing with something that one does not know how to deal with. We eventually contacted a local politician in our area and we got an appointment. We went to CAMHS and it spoke to our son. He explained that he was hearing voices and that the voices were telling him to kill himself. He was terrified. He was seeing shadows and hearing footsteps. He was convinced, especially at night, that someone was coming to kill him. My son was terrified. He was told that the voices are not real and that he should not listen to them. That was not enough of an intervention for him.

We were told that our son needed to be watched 24-7 and that he should be physically restrained if necessary. Every night he would be so scared that he would cry, scream and try to run out of the house because he felt that something was chasing him. He would eventually fall asleep in my arms, exhausted. My partner works nights, so I would be at home with my son on my own. I remember that I was awake for almost 72 hours straight. My eyesight went fuzzy and I had a headache. I did not feel tired anymore, but I did not feel alive either. On one occasion I was so terrified that I would fall asleep I walked up and down the hall with a cup of

coffee in my hand at 3 o'clock in the morning. We knew that this could not continue. We had Rhys in the bed with us sometimes but he did not want that. He was almost 13 years old and sleeping in between us was not acceptable, so we bought a bed and put it into our room. For safety we locked him into the room with us every night, and at least that way I could sleep and Rhys could possibly sleep as well.

On another night my son attempted to seriously self-harm and we took him to the emergency department because it was out of hours. Rhys and I were put into a small waiting room and we had to wait for over two hours for the on-call psychiatrist. Rhys escaped from that room that night and ran through an emergency department full of adults screaming, "Please let me die". He was trying to escape from the hospital and get outside. He said that he wanted to run under a car and die. I took flight after him. Security and a nurse did likewise. We caught him and had to bring him back. It was so distressing. We were in this room and all these people were looking at us. It was awful. An emergency department is not the answer. It is not able to deal with this situation. The environment is wrong. It is not very safe. I was in that room with him and he was still able to get out of that room. It is not a suitable situation for a child. When we saw the on-call psychiatrist that night he was put on medication to calm him and help him sleep, but he was sent home that night. He slept in between us. He did not really sleep but spent the night hitting his head in an attempt to get the voices out.

In subsequent months, we were over and back to CAMHS regularly, but he did not improve much. When there was a small improvement, even if he had said that he wanted to die on the same day, he was discharged. Only two weeks ago Rhys attempted suicide. He left a suicide message on my phone. To me that is an escalation. He is thinking more about what he wants to do. He was saying goodbye to his mother and telling me that it was not my fault. My partner caught him, thankfully. He is now being seen by CAMHS again. He is on stronger medication, but the sad reality is that medication is not always the answer. He needs psychology. We have been told that he is not going to receive this from CAMHS. He is now on a waiting list in the disability services for psychology. He has been on that waiting list for almost four years. This psychologist does not exist in our area. There is no psychologist for a child over six years of age. Why is that? How can that be? My son is one of many children who need this help. CAMHS is overworked and understaffed, which is unfair on it and its clients. The waiting lists are far too long for children who need help now. Children presenting with suicidal and mental health issues cannot always wait for 12 months. They need action now.

I want to point out that there is no out of hours service for children with mental health issues. There is no safe environment for a child to go into an accident and emergency department presenting with mental health issues. I would never allow my son to be put into an adult psychiatric unit. This should never happen. It is not acceptable or appropriate. As a country, we need to improve these services, open more children's psychiatric units and have more psychiatrists and psychologists available for our children. It is not okay for a child with suicidal thoughts or who has attempted suicide to be put on a waiting list. They need help and intervention and they need it now. This is a basic human right which our children are being denied. Our children deserve better treatment, and their well-being needs to be prioritised. Unfortunately, this is an ongoing issue for my son, who is telling me that he has given up and that he just wants to die. I believe him. He does not want to feel pain any more. As a family we have been badly affected by this. We cannot go out with our friends. We cannot bring him to his favourite places, such as the zoo, anymore. If a place is too crowded he gets too stressed and is hearing things that are not there. He is afraid to go out and play sometimes. We are at home all day, every day. He just wants to go to school.

I want my little boy back, that beautiful, happy little child that had so much energy and loved living life. I need him back. He needs to come back. Can anyone imagine being a parent and seeing this awful transformation occur? We have tried everything in our power but it is clearly beyond the parents' control. I am scared that my son will achieve his goal. I am scared that he is going to die. I want my son to get the help he needs. I want to get my once happy little family back, and I want my beautiful boy to get his confidence back. He once said that he wants to become an animal biologist. I want to see him achieve this goal. I want my son to go out and play, like any other child. I want to have to ring him to tell him to come home as it is late, like any other parent, and not to sit at home with him watching to see if his mood is tipping and have to shadow him in case he tries to harm himself. I am asking this committee to help my son. I am asking the committee to help every child in our country presenting with these issues. Today I am asking the members of the committee to think, "What if this was my child?" What can we do to help this child? How can we move forward?

Ms Louise Walsh: I have three boys. We had no problems. I had three perfectly normal kids who were very intelligent, high achievers and very good in school. One of them won the south-east maths challenge. He is very brainy. The other guy was awarded for his abilities in Irish. I never had any bother with my kids. I want to show the committee a photo of them. They are brazen, good kids. They play hurling. One is a boxer and the other fellow does MMA. We are just a normal family. I did not have any of the problems that the girls have had, thank God. Then, in October 2015 my partner died suddenly of a heart attack. Our world was rocked. It was swept from under our feet. I had been a special needs assistant for almost eight years. I had been made redundant and in the meantime I got a job working in Revenue. I was due to start in Revenue the week after my partner died, but I had to postpone it. I started after two weeks. My kids were back in school. We had to rebuild our lives after my partner died. I wanted to try to get a normal life back so that they had a good foundation in everything. I went to work and we did our best to get by. In January I found out my eldest son who was in fifth year had been going to school but he had been coming home every day about 11 a.m. or 11.30 a.m. and getting into bed. He could not cope with life. He could not cope with school. He was suffering with severe depression brought on by grief after losing his dad. I took some time off work and brought him to the doctor. The doctor rang the nurses 24-hour suicide helpline but he was too young to be helped. He was just after turning 17 so he was not eligible for the service. The doctor said that he should do exercise, do everything. We followed all the advice. He played sport and we did everything but it was not working so we went back to the doctor and the doctor and I begged him to please present himself in accident and emergency as he was suicidal. He wanted to die as he could not go on. We told him that the only way to get access to the services was to go to accident and emergency because there was a ten to 12 week waiting list for CAMHS and he just could not wait. We went three times to accident and emergency. He was put on Prozac and quetiapine, an anti-psychotic drug. He was 17 years of age and he was put on drugs that have warnings on them that children should not be on them as they increase the risk of suicide. He was put on those drugs and we were sent home. Things went from bad to worse. I could not go back to work. I had to take time off work. My other two children were watching that. They were 13 and 14 at the time. They had just lost their father and they were at risk of losing their eldest brother at this stage as well. That was the reality. We had a double grave and there was a good chance we were going to use it in six months.

The fourth time my son had gone out, he had about five pints. It was March. He was 17 and he had a few drinks. He came home and he was as happy as Larry. He got a Chinese takeaway. That night everything fell apart for him. He told me he had a noose in the shed and he had tried to hang himself a couple of times. That night he said he could not take it anymore

and he begged me to let him die. He pointed to a guy on the street who had alcohol issues and he said to please let him die as that was all he had ahead of him. He said he had nothing ahead of him only to be a drug addict or an alcoholic. He said if I loved him I would let him die. I rang the Garda and I rang an ambulance that night. The Garda came after about half an hour and my two sons were out on the road watching for the Garda to show them where we lived. I was physically restraining a 17-year old boy. My brother and my father had come to the house at this stage to try to help me. He had broken up the bathroom. He had put his head through his bedroom wall. He was trying everything to get the pain out of his head and nothing would work. He said he had done everything I had asked him and everything the doctors had asked but nobody could help him. He said he just needed to die. He said I would get on way better and the lads would be way better if he was not in our lives. He said we would soon realise that the best thing for this family was for him to die.

When the gardaí arrived at the house I was physically restraining him on the couch in the sitting room because he was trying to get out to the shed and he was trying to get access to a knife in the kitchen. I had my arms wrapped around him trying to hold him, trying to stop him killing himself. The gardaí came. They asked what I wanted them to do about it. I said I wanted them to help me save my son's life. I said I called them to help me save my son's life, that I could not do it on my own. I asked where the ambulance was. They said there was no ambulance coming for him. They asked what I wanted an ambulance for and that they would bring us to accident and emergency and drop us off. I said "no", that I had been to accident and emergency three times and that he could not sit there anymore, that he could not do it. The gardaí refused to ring an ambulance for me so I sent my 15-year old out to the hall and I asked him to ring the ambulance. Eventually, the gardaí said they would get an ambulance for me. They told me that if my son continued they would arrest him, so I had to ask them to leave my house. In the end, they stayed as I think they realised what was going on. We were basically being labelled as a mother who has a brazen teenager who would not do as she says. That is how I felt that day. They asked me what he had taken and what he had been on. I said he was not on anything. I said he was suicidal and he was suffering from grief.

We went to accident and emergency that night when the ambulance came. My son, a fit and healthy 17-year old who was supposed to line out and play a hurling match the following day was brought in on a stretcher and wheeled catatonic into accident and emergency from an ambulance that night but he was alive. We spent that night in accident and emergency. I sat in the waiting room watching all the ads, such as "It's ok not to be ok", "Ask for help" and "Tell someone". That is absolute rubbish. There was nothing there for us when we went looking for it. It is a complete and utter contradiction and it is hypocritical. There was nothing there. We had been everywhere looking for help.

My son spent the night in accident and emergency. On Saturday at 9 a.m. he was brought down to the adult psychiatric ward. He was told that he would not be allowed to leave his room because he would be in danger from other patients there. He said he was not staying locked up in that place. I begged him to stay. He got up and he ran out of the hospital. There was a big lock-down. All the alarms were put on in the psychiatric ward. He slammed his head off a concrete wall and he was brought into a padded room. He turned around and he said, "Do you believe it. It is like Bobby Sands' room in here." He was a 17-year old boy whose father had died and that was what we got. He was in that padded room. They asked me to leave so they could calm him down. I left. I came back an hour or two later and he had been given a room. There was no staff. They had nobody to mind him. He was in danger from other psychiatric patients. They had to get an agency nurse in to mind him and to sit with him 24/7. I had to bring

him in pyjamas. I had to take the cord out in case he hanged himself. I had to take the cord out of the hoodie he got from Santa in case he hanged himself. He was not allowed his bag. It was locked away. He was not allowed anything. He went in on Saturday morning.

We only saw a doctor because he poured a cup of coffee over his head to show me that he hated the place so much and that if I did not take him home he would kill himself, so he was physically examined to make sure he had not damaged himself. Thank God the coffee had cooled down enough so that he did not do any damage. Basically, he was left in that room until Monday evening. Nobody came to see him. We were told there was no child psychiatrist in the hospital and there was nobody there to see him. On Monday morning I asked what was going on and said he had to be seen by somebody. I told the doctors that day that if I had known that this was what was going to happen I would have just hired a security man to come and sit in his bedroom because we would have been better off. We waited all day for a child psychologist. The child psychologist in Wexford hospital had to finish her rounds before she could come to Waterford. There was no one to see him. I asked where the doctor was and she was upstairs on another ward seeing another patient. I was raging. I asked how any other patient in the hospital was more important than my son who had been in there since Friday night in the acute area of an adult psychiatric ward on lock-down. I asked who in the hospital was more important than him that he or she was seen before him. We had waited all weekend. At about 7.15 p.m the psychologist eventually came. I asked what they were going to do but I was told there was nothing they could do but that I had the option of sending him to Cork or Galway. I could not believe it. They were telling me to send my son to Cork or Galway, that he could go to a adolescent care centre there for psychiatric problems. I asked them how they seriously expected me to be a parent in Waterford and a parent in Cork or Galway at the same time. I could not do it, financially, physically or in any other way. The option I had was to leave him in the hospital. I was told it would take about two weeks to get a place for him and that I could leave him in the acute psychiatric ward in Waterford until a place became available or I could take him home.

I took my son home that night, knowing full well he might not make it but I could not leave him in that ward a minute longer. We went home on his promise that the next time he wanted to kill himself he would tell me about it so I would help him get through it. The threat was that if he did anything behind my back he was going back into the ward. We went home and I sat in his room night after night. I took him off all the medication and I minded him myself, with my family, and we got through it. We went to private counselling and we got through it.

He tells me he will never ever get over being in that ward, and that it did more damage than anything ever done to him in his life. He is fine now. He asks me how I could do it to him. Now he is out of it everything is okay and he knows I had nowhere else to go. I trusted a health service that was supposed to be there, that advertises everywhere to get help and to come to it and it will help, but there is nothing. To be honest, I would not advise any parent, no matter how bad the child is, to put him or her in an adult psychiatric ward. It is the worst thing ever. I brought him home knowing I might lose him, but if I had a choice of that or leaving him there that is the choice I made.

He telephoned me from the hospital when I went home one night and he begged me to speak to his brothers. I asked him what he wanted to say and he said he needed to say goodbye because he would not be there the following day. I told him I could not leave him do that. He told me I could not deny him the chance to say goodbye to his two brothers. He told me he could not survive another night in there. That is what we went through.

We are, in a sense, everybody sitting here. Anybody sitting here could lose his or her partner

in the morning. Their life could change. We are anybody. We are the children picked up and ferried to GAA matches. We are everybody. We are a normal family who looked for help. We have suffered enough. I buried my partner. They carried their father's coffin. That is what he had to go through and that was the help we got. Last week, when I told him I was doing this he told me he hoped the people here realise how hard this is, because this is not my story this is my son's story. It is easy for me to speak because I did not go through what he went through. Last week I told him if we can stop one other child going through what he had to live through something good will have come out of everything. He told me if he had lived in any other family he would be dead and that he would have managed to kill himself. I had great support. My father, my brother and my in-laws were fantastic. Other than that, my son would not be here. He is fantastic. He is doing an apprenticeship and he is absolutely brilliant again. He is so aware of mental health now. It is so important this is made into law. It cannot happen to anyone else.

Ms Sinéad McGee: I am little choked up after hearing these ladies' stories. Unfortunately, I also have many stories which are quite similar and sad. I thank everybody for inviting me here this morning. It is a great honour. I am the chairperson of Dublin city and county CAMHS carers forum. We come up with ideas and suggestions on improving the service. As part of this I attend a monthly management meeting. At present, our goal is to run coffee mornings to support parents and carers because when our children are not well we go through an awful lot ourselves. It is a constant battle for us.

Through this, we have found issues in the service, which I will run through quite quickly. There are waiting lists and waiting times to access the service. There is a lack of autism services. There is a gap for people who have mental health issues but who are not severe enough to be seen by CAMHS. In the Dublin north county area there are no primary care psychology centres. There is a lack of professional expertise in CAMHS and not every discipline is available on every team. There is a difficulty recruiting and retraining staff. Many locum and temporary staff work on each team, which leads to staff turnover. This has an enormous impact on our young children who have to start all over again with new therapists and have to tell their story all over again. I have no words for the placement of children in adult psychiatric wards. The young person has so much going on already. I cannot even begin to imagine the impact this has on young people and their family. There is also a huge concern for those aged between 18 and 25 in mental health services. We need to look at having a youth mental health service for this age bracket. It is a huge transition to go from a child service to an adult service.

As I am the chairperson of the carer's forum I have some letters and stories of real-life situations of what parents cope with, some of which I will share. I find them all moving and I have my tissues to hand.

One family has a very active suicidal 16 year old boy at home and they have been so fearful of his safety that they have had to take him to the accident and emergency department. As he is 16 this is at an adult hospital, which is very scary for an adult never mind a young person. They get referred to CAMHS. They then get their son home from hospital after having the talk from the doctor about safety issues, such as locking away tablets, making sure no knives are left out and making sure there is nothing he can put around his neck or anything with which he can harm himself. They safeproof their home and then they wait as the vigil starts. They continually watch out and no one sleeps. Siblings and family are in turmoil with it all. They are trying to help him stay alive. They are the last hope trying to do the job, the resuscitating and the ventilator, keeping him safe for goodness knows how long, to try and get the help he so desperately needs. Every day feels like a lifetime. Every night is endless. "Just keep him

alive” they keep telling themselves. Everyone says to ask for help when someone does not feel in a good place but when people do it is not there. Their lives are on hold.

Another parent who wrote had to leave a €660 a week professional job that the person loved to take what is described as a €300 a week horrible job in a supermarket to be at home at the same time as the person’s daughter, who was waiting for the service. The person was afraid to leave her at home alone. That decision will impact that person and the family for ever. It is not exactly a decision that can be explained on a CV. That parent stated immediate and local services would save lives and children do not shut down for the weekend. The service from 9 a.m. to 5 p.m., Monday to Friday, is definitely an issue.

Another family wrote to say they had a 15 year old son who was suicidal and came to them after putting a knife to his throat. He cried for hours and did not want to live due to bullying at school and the pressures of fifth year. They got an urgent referral to CAMHS. He was walking the floors every night and they had him on 24 hour watch. They telephoned CAMHS daily they were so worried. A week later they got an appointment for three month’s time. Their son was still suicidal and they had not slept, making sure he was okay.

Another parent wrote to say hers is not quite the usual story. Her husband took ill last October and by the end of November they knew he was terminal. Both her children have ASD, ADD and dyspraxia as well as some medical issues. She tried to get advice from the service on how to tell the children about their father. She left messages to telephone urgently but could not get past reception. Eventually her husband had to go into a hospice where the medical social worker also tried to make contact. The service eventually got back to her, which took a couple of weeks, but by the time it did it was too late. Her husband passed away in April and she was sent an appointment for 4 July, which was too late. Another parent noted how they could never stop watching them or ever relax. They felt isolated and wished that someone could do something to help them. If not, they felt, their kids would die. They feel our children should be our priority.

A 36 year old man is trying this best to go to work with his daughter very unwell. He is fighting to try to get support for her. His relationship with his wife has also been very strained with the stress of the situation and he now knows what depression is. He felt extremely down one of the days, at his lowest point, and his little girl came over to him, grabbed his hand and said, “Daddy, you are very strong”. He said that, if anybody ever needed to say that to him at that moment in time it was his daughter. She could see how much distress he was in over her sibling.

Another parent wrote that their 13 year old daughter was currently on the priority waiting list for the local CAMHS. They said the relief of seeing the words “priority waiting list” felt so good and hopeful that they rang CAMHS to find out what it actually meant. They were told they were looking at months on this waiting list for their young child, who had a moderate to severe mental health issue, because that is the criterion to get onto that waiting list. They asked how they ended up where they were. Their daughter had, over the past 12 months, become very withdrawn and slowly started to lose interest in pretty much everything. In the past three months they have found it very hard to get her to do anything or go anywhere. Simple tasks like getting up and getting dressed seem to be too much for her. As a family they tried very hard to encourage her to join in any social events in the community. However, this resulted in their home becoming a breeding ground for tears and anger, instead of the loving, warm home it was and should be.

Now, the daughter has absolutely no interest in anything. In the past few weeks, they came across letters that she wrote, with words like “I want to say goodbye”, “It’s never going to change”, “I am hopeless”, “I don’t want to do this anymore”, “I feel invisible”, “Nobody likes me”, “Nobody cares” and “There is no point in living anymore”. The parent has now had to leave their job as they cannot be at work and not know if their daughter is safe and alive. They asked me to imagine what it would be like if my child had thoughts like that every single day, and to picture the waiting list and the prospect of sitting there for months. They feel constantly in a crisis, like they are not living any more but just trying to get through each minute, hour, day as best they can. It feels like all their lives are on hold and they are on constant watch with their daughter. They do not know if they or their daughter can get through this. She desperately needs help and support but she is on a priority waiting list. They hope they do not run out of time as they are scared.

Another person speaks of having personal experience of a daughter attempting suicide. She had collapsed at home and was going in and out of consciousness. The parent had to take her to the emergency department with no idea of whether she would survive. The parent held her hand, full of fear of what was to ahead. The daughter could have died that day. She needed help but so did the parent. She was not doing this for attention but to end her life. They were referred to CAMHS and had to wait two weeks for that appointment, two weeks that seemed endless. They had to have her on 24-hour watch for that time and went into crisis coping mode, just getting by, doing everything they possibly could for their daughter but not being able to even think straight. They were isolated and alone. They had to back away from any volunteer work within the community as they just could not focus or function. Looking back at that now, this parent still wonders how they got through that time. They cannot imagine how parents can live like that for months when they struggled for those two weeks.

I was contacted by two other parents recently. It breaks my heart to read these letters. I have had my own personal experience and I know how hard this is. One parent had a four year old, the other a five year old child, and both are having suicidal thoughts. They do not qualify for CAMHS because they are too young. I cannot imagine what it is like for the parents - it is so sad. There should not be a waiting time of months for families such as these. It is wrong and unfair. Mental health issues are so hard for a family to cope with and it is crazy that a vulnerable young person has to wait months to be seen. Their lives are put on hold as they go into survival mode. Our young people matter and they are our future. The situation needs to change as soon as possible.

Ms Martina Kelly: I am Martina from Sligo. We are a family of four. My husband is Liam. We have two sons, aged 21 and 17. We adopted our second son 14 years ago when he was three, from Belarus. Adopting was a very difficult path that took five long years of assessments and social workers. We loved him from day one and have always done our best for him. When our son started national school, aged five, his teachers noticed that he had difficulties. He was hyperactive and could not sit still. He was overboisterous and exceptionally noisy. He constantly spoke out of turn and was very disruptive. Playing in the school yard became a big problem and in the classroom he made teaching and learning very difficult for everyone.

Our school referred us to the HSE and through the school’s help and persistence we finally got an appointment for our son to see a child psychologist. Over a period of two years she assessed him and eventually reported that he had severe ADHD. The psychologist then referred him to CAMHS. We were told that once we started attending psychiatry we could no longer avail of psychology. We would like our son to have availed of both services as we feel he has

both psychiatric and psychological problems.

Over the following seven years our son was seen once every six months by a different psychiatrist at each visit so we could not build up a relationship with any psychiatrist. At every appointment, none of the psychiatrists talked to our son. They checked his height, weight and blood pressure and we were always asked if we wanted to increase his medication. Every time I tried to discuss his problems I was told it was behaviour. They offered no advice and no help. Finally, in the past two years we have built up a relationship with a part-time temporary psychiatrist who has stayed and will stay until a full-time permanent psychiatrist is, hopefully, found. This part-time psychiatrist talks to our son and does not worry about his height or his weight.

ADHD has created enormous difficulties in our family, our home, our community. Our son never thinks of consequences. He does not comprehend dangers and he enjoys dangerous behaviour. He is a risk-taker who craves excitement and his mind is constantly on overdrive, racing off in very unexpected directions. He is very intelligent and sporty but he cannot stick with anything. He was a great Irish dancer who won many trophies and medals and various feiseanna over several years. He was a great rugby and soccer player and he enjoyed horse riding and surfing. Sadly, he has abandoned all these activities. He gets bored and frustrated very easily. This leads quickly to agitation and anger, and sometimes violence. He does not like his life being so chaotic. He attends all his appointments, takes his daily medication and engages in every help offered to him. In June 2016 he did a very good junior certificate. Unfortunately, he refused to go back to school in September. In autumn 2016, we tried to get him into various courses but he could not stick with any of them. He was restless and rudderless, with no school structure or routine. He started staying away from home for two or three nights, with no contact with us. He would not reply to texts or answer calls. He started drinking alcohol and experimenting with drugs. He became friends with men and women in their 20s who were all eight to ten years older than him. We did not know these adults. We did not know where they lived. It was very worrying and frightening for us.

Our son's life started to spiral out of control from November 2016 to May 2017. During this period, he was found unconscious on town streets overdosed on either alcohol or drugs. He did not care if he lived or died. He was hospitalised on several occasions. During this period, we were in constant contact with CAMHS and Tusla begging for help. In spring 2017, Tusla held a multidisciplinary meeting for all parties to get involved in an in-depth discussion about our son's problems and how best to help him and us. A week later, we were asked to meet our son's social worker and the senior social worker. After a lengthy discussion, we were told their big solution was for us to go home and to try not to fight. We left that meeting feeling deflated, disappointed, disgusted. After this meeting, things got worse for all of us.

During the first week of May 2017, our son tried to take his own life on several occasions. On the bank holiday Sunday, he took a drug overdose. He was rushed to hospital. On the Tuesday night, he went into respiratory failure. He was rushed to hospital. On the Saturday night, he jumped in front of a car. He was taken to hospital. On the next Sunday, he took an overdose of non-prescribed household medicines. We took him to hospital. All this happened within seven days. All these traumatic situations occurred at weekends or night times when we could not contact CAMHS or Tusla. The emergency department did not know what to do with our son. On some of these occasions, he was kept under 24-hour watch because he was a danger to himself and others. On one of these occasions, he was left sitting in the emergency department for 13 hours without any help. On another occasion, we were told we would have to wait at least 12 hours before he could be seen by a doctor so I brought him home and sat watching him

for 24 hours. During this crisis week, I rang CAMHS and Tusla crying for help. I asked for him to be admitted to a secure mental institution or strict high-dependency residential care for his own safety. I was told by CAMHS and Tusla that they had nothing to offer us. We were told there are very few beds for teenagers with mental health problems. We were told that even if they found him a bed there was no guarantee he would stay as they could not force him to stay. He would be free to walk out any time he wanted. This was the worst week of our lives after six horrendous months of living through a nightmare and no one could help us.

Five weeks ago, he started a Youthreach programme. He plans to do the leaving certificate applied through Youthreach over the coming two years. He has stopped taking drugs. He is trying to cut back on alcohol. He attends a drug and alcohol addiction counsellor weekly. He is making every effort to take control of his life but we fear for his future.

As in our case, most incidents occur in the evenings, at night time or at weekends when Tusla or CAMHS cannot be contacted. Several times in the past six months we have had to call in the Garda at night time when we should have been calling a social worker. Gardaí are not trained social workers, psychologists or psychiatrists but they are expected to be all three when a crisis occurs at night or on weekends. In our experience, we have found most gardaí to be excellent mediators and very helpful and understanding, especially our local gardaí who know us and our history.

After many years of asking for our son to have a psychological assessment, we finally got the assessment done in June 2016 while our son was also doing his junior certificate. In autumn 2016, the psychologist told us she had completed the assessment and she would forward the results. To date, after waiting 12 months, CAMHS, Tusla or ourselves have never received any assessment report. In the nine years we have been attending CAMHS, our son has never had a psychiatric assessment. We, his parents, believe our son has psychiatric and psychological problems along with severe ADHD. Due to a lack of both funding and staffing, we find it very difficult to get answers. Our son is crying out for help so I ask the committee, "Who do we turn to for help, especially at night and on weekends?" I have just one last thing to say. Yesterday, we attended a multidisciplinary meeting in Sligo. Every organisation and service was represented, except CAMHS. CAMHS had no one to send to our meeting.

I thank the committee for inviting me to speak and for listening to me.

Chairman: I thank Martina. I thank you all. I will take questions from the Senators. I would ask them all to be brief and to the point, and the witnesses will respond. I suggest we take an hour and a quarter for this session of questions and answers. That will allow us to adjourn at approximately 12.30 p.m. because we will be on again in the afternoon. I call Senator Byrne.

Senator Maria Byrne: I thank all five ladies for their moving presentations. There is a common theme running through all of them, namely, that those under 18 have fallen through the cracks because they do not fit in with adult services.

The HSE report stated that only eight out of the 17 provide weekend services. That is something we need to focus on because, from listening to the witnesses, it is out of hours - after 5 p.m. and at the weekends - that they find there is a lack of services, a lack of co-operation or a lack of staff to be able to see to the needs of their sons and daughters and the many children who are affected unfortunately by mental health issues. They all put together fine presentations and I am very sympathetic towards their case.

On Tuesday, I visited a community centre at which a new autism unit has been opened. This unit is children aged between three to six years. Even though I had been in a number of services in the past with different people, it was a moving experience to see the very small children's needs and to see the way that they had built up over a couple of months a working relationship with the teachers and that the parents were brought on board. It is important that we start early at a young age, but obviously the witnesses were not aware of that because, for the majority of them, it is as the children got older that issues started to arise.

The committee needs to look at the out-of-hours services and the lack of needs for the under 18s because that is very important. I thank them for their presentations. Certainly, I have taken them on board.

Chairman: Can I take Senator Devine, briefly? Does the Senator wish to ask a question.

Senator Máire Devine: I will do my best to be brief.

Chairman: At this stage, I will be trying to keep everything brief but as best as possible.

Senator Máire Devine: I say, "Well done" to Lauren, Paula, Louise, Sinéad and Martina. I introduced myself as having a long career in psychiatric nursing. On this side of the Seanad, a lot of us are really working hard. Senator Joan Freeman is making sure that we really work hard and give our hearts to making sure our mothers, fathers and siblings are all safe and our children are safe.

To start off, I want to mention Linn Dara . I have raised it every day in this Chamber since the beds were closed. It is utterly unacceptable. They just do not get it and that is what we need to keep saying, again and again.

There is so much that I want to say but, obviously, I have been told to be good. There are lots of themes emerging.

Chairman: Sorry, this session is meant to be questions from the Senators to the witness-----

Senator Máire Devine: Okay, I am just making an observation.

Chairman: -----in case we go off the rails altogether.

Senator Máire Devine: There are lots of themes emerging. They say it is the family, it is the children. Where are the supports for families? It seems they are just left behind. Even if the services eventually get to the child who is having difficulties, the family is never addressed. When the child gets to the hospital, it wants to discharge him or her and says it is up to parents who have no plan and who are left in the dark, without a clue. Parents have to sleep beside their teenage son or daughter 24-7 to keep the child safe. I do not think that is acceptable. The financial cost of speeding up the process to try to get help involves losing one's mortgage and putting one's house at risk. There is not just the financial cost but there is also a cost in terms of lives not lived in that happiness should be at the core of the child's life and he or she should experience the world around them.

The other observation is that a United Nations International Children's Emergency Fund, UNICEF, report came approximately two weeks ago which stated that of 37 nations, Irish children aged between 11 and 15 are at the second highest in terms of saying they have emotional issues on a weekly basis. That is fairly stark and it sends a message to us all. Does the Chairman want me to hurry up?

Chairman: I am beginning to think the Senator does not have a question.

Senator Máire Devine: I know it was in an adult context but in the 1990s we set up a crisis intervention team with the nursing union and the HSE that worked within the community. It was very successful. It stopped admissions to hospital. It proved financially prudent and it provided care. I would go a person's home, as a professional, and sit with him or her until the crisis was gone or until that person said that he or she would get an appointment to go to see a psychologist or psychiatrist. I would not leave that person's home until that happened, because I would help him or her to keep his or her children safe. We need to do something like that.

Unfortunately, with the cutbacks and the downturn, the approved centres are the priority for staffing. That all fell apart, but it was fantastic and it was financially, which is what Government listens to, and emotionally good and it kept many safe. I think we could adopt that for children. I have much more to say but I feel a bit of pressure from the Chairman.

Chairman: We do not have room today for Second Stage speeches. We all have questions to ask. I thank Senator Devine and call Senator Freeman.

Senator Joan Freeman: I have three very brief questions. I keep referring to the witnesses as "the warriors". Before I ask the questions, I acknowledge the presence of the Minister for Children and Youth Affairs, Deputy Katherine Zappone. I thank her for attending today.

Chairman: I did not see the Minister but I welcome her.

Senator Joan Freeman: I offer the Minister my deepest sympathies and condolences. She is here today to listen to these women, and I appreciate that and thank her. I welcome Deputy Pat Buckley as well.

The three questions I want to address are for clarification. They are for Ms Lauren Keogh, Ms Paula Dalton and Ms Martina Kelly. Did Ms Keogh say Zara, her 13-year old child, developed anorexia while on a waiting list? Could she expand on that?

Ms Lauren Keogh: Zara was seen to under the assessment of need initially. I had many concerns, all of which were dismissed. I was only referred to the child and adolescent mental health service, CAMHS, waiting list when I challenged it. I asked how observations from a professional could be dismissed. As I said, I was absolutely delighted because we were getting services and I thought they would come soon. We were put on that waiting list for 18 months. Two months into the wait, she developed anorexia and suicidal thoughts. As a result of that delay, she unnecessarily had to battle anorexia for over a year, purely because it was not a proactive approach, but reactive, which is the same in all the cases mentioned here today. That is a big thing that I need to stress coming here. It is very reactive, and even at that, there is barely a reaction. People are shouting and screaming but no one is listening. There is much waste.

Zara had her first psychology appointment two weeks ago, with the disability team. She should have had it a long time ago when we were first referred for assessment of need, but because we were hopped from one waiting list to another, after two and a half years, she had her first appointment. I was sitting outside waiting for her, and I was flicking through a magazine. I came across this fabulous article about a website the HSE has. It is called *informingfamilies.ie* and it is fantastic. All the information is there. Parents do not know about it. Professionals dealing with this do not know about it. The amount of information on that website is unbelievable. It is a huge resource. One can tell much work has gone into it. It was set up in 2009, reviewed in 2015, and to this day, and I have plenty of contacts in this circle of special needs

parents, nobody knows about it. It is a huge waste. It would have been very beneficial if people had been told about it. Such things are not proactive, but are very reactive.

Senator Joan Freeman: My colleague mentioned accident and emergency departments, but we are also looking at the problem of waiting lists. There are 2,500 children on waiting lists, and Ms Keogh said that Zara developed anorexia while on that waiting list.

Ms Paula Dalton mentioned that Rhys waited for CAMHS for 12 months. Did she tell it during that time that he was suicidal? When she eventually brought him to an accident and emergency department, there was a three-week waiting list. Did people at it know how critically suicidal he was?

Ms Paula Dalton: I voiced it and the accident and emergency department got a referral from the autism spectrum disorder, ASD, saying this as well. It had received a referral from the ASD team and a letter from a general practitioner. I had been ringing and voiced concerns to say that the previous night, he was hearing voices, or whatever happened. I made those in the accident and emergency department aware.

Senator Joan Freeman: So they were aware of that. Ms Martina Kelly went through years trying to get help for her son. Does she believe that if there had been early intervention for him, he would not have ended up self-medicating with alcohol and drugs if he had been seen to as a child, or at the time when he needed it most?

Ms Martina Kelly: He is a risk-taker because of the attention deficit hyperactivity disorder, ADHD, and he got early help because the school saw that he had huge problems and pushed for it. I think we got in reasonably quickly compared to many people, because the school spotted he had problems at the age of five, and he was with a child psychologist from the age of six until eight, and he got into CAMHS when he was eight. I felt that we were lucky to get into the system fairly quickly, but I feel that the system let us down when we were in there. We even had an appointment yesterday but nobody from CAMHS was sent. There was somebody from every discipline there. There were ten people around the table, but CAMHS could still not send one person. We were all given plenty of notification. Even when we started with CAMHS, it was one appointment every six months. Much can happen in six months. The people in it did not even want to discuss anything with my son and did not even ask him a question. The only question they asked every time we went in was if I wanted to increase the medication. They did not want to have any conversation at all. We were the lucky ones getting into the system, but the system let us down. My son attended every appointment he was ever given. He was very co-operative. We did everything we could possibly do but the system still let us down.

Senator Colette Kelleher: It is very generous of the witnesses to bare their souls to us this morning. It cannot have been easy. We hope that we will be able to act on what they have told us. They are all mothers. They do not seem to have been listened to a great deal by those in the system when they got into it. What helped or would have helped so that we can put that in the report and hear what they have to say? Each will have a different story, so I would like to hear from them about what actually helped or what might have helped had it been there, so that we can put those recommendations directly into the report.

Chairman: The witnesses can answer in turn. I ask them to be as brief as they can. I call Ms Lauren Keogh.

Ms Lauren Keogh: The first thing is having the ability to advocate. As a parent, it is a

problem if one does not have that mental capacity or fight. It is important to have supports for parents so they can advocate, identify knowledge and educate. Parents are very reasonable. They are very willing to get involved and safeguard their children but they need to know where to go to get the tools to access the support, to advocate and to identify their children's needs.

The second point is that there should not be two separate teams, a disability team and the mental health service team, working in two different ways. Patients are moved from one waiting list to another. We should not have had to go near the child and adolescent mental health service, CAMHS, if the disability team had the right resources and enough staff to read the reports, to give the matter enough attention and to listen to our concerns. It has a huge impact on a parent not to be listened to but to be seen as exaggerating. My child has high-functioning autism. She could come in here, sit and smile and look people in the eye and have a very normal conversation but outside she will have a full-blown meltdown. The staff do not see everything in a 40 minute meeting.

Siblings are completely forgotten about. It does not have to cost a fortune. The disability team could organise something as simple as peer support, a sibling group, for example, if CAMHS had one room free on a Wednesday morning every two weeks, or every month. Ms McGee mentioned that a coffee morning is coming up where she is based. That support for parents to connect and bounce ideas off one another would help. The treatment needs to be meaningful, not just ticking a box which is what is going on at the moment. Everyone is so concerned about getting on and ticking the box.

Ms Paula Dalton: Support for parents is very important. I have been lucky in having close family and friends who have helped us but not everyone is in that position. It would be lovely for children if there was a centre where children could go to play a game of pool and talk to other children dealing with similar issues to let them see they are not alone. Rhys feels very alone. He feels no one understands. This isolates him. That is true of all of them to a degree.

Rhys is autistic but the first thing we heard in the CAMHS was that our son had autism, and CAMHS did not need or did not have to treat him. My mouth just hung open because I did not know how to respond to that. He is autistic and he is highly intelligent. He probably has a higher IQ than most of us in this room. He is a delight and he does benefit from treatment and services. The disability services and CAMHS should come together and talk about this child and other children. They are so busy passing the buck between one another that this little child is falling between the cracks. It is getting worse and a lot of time and money is being wasted. I have noticed that since the autism spectrum disorders were brought into the mental health sector. That needs to be highlighted.

Ms Louise Walsh: There needs to be a crisis centre. There is no point in telling a parent to bring the child to the accident and emergency services. We were there too many times and on the third occasion there was a group of young fellows around my son's age and one of them had got hurt playing hurling or football. My son should have been one of those but he was there for a different reason. He could not sit in accident and emergency. He had to sit outside and he said he could not cope because he was not able for it. He could not cope with the people. He sat outside in the cold. I told the nurse we were outside the door. She did her best. She tried to accommodate us and she brought us into the family room to wait. The family room was the only room available in that accident and emergency and it was the same room my three sons had been brought into to discuss their father's death and what would happen next. That was the only facility available for us that night.

There needs to be a crisis centre in order that we are not ringing the Garda or accident and emergency and going through that hullabaloo. There needs to be an emergency line that a parent can ring and say his or her child is in crisis and he or she needs help now. It could even be only a room where a parent could sit with his or her child and make a cup of tea and not be judged by people who are in with broken legs or all the other traumas that one sees in accident and emergency. That is hard to cope with at the best of times but for someone aged 17 who is trying to kill himself, that is not the place to be. Every hospital in the country should have a crisis centre, not just for children but for adults as well. If the parents are told they have to wait four or five hours for the on-call doctor to come to see the child, there should be a safe place to sit, next to security, to keep their child safe and to be safe themselves as well. That is what I have seen that is not fair.

Ms Sinéad McGee: We need a service for the less severe range of mental health issues in our children. Let us not wait until they have got to the point of attempting suicide. We need to nip it in the bud. Maybe that is not an issue for CAMHS but for the HSE to provide psychology services within the community. There are no psychology services for children younger than 18 in north county Dublin. We need more staff. Many of the staff in CAMHS who I have been involved with are temporary or locum staff. Recently, they lost a really good psychiatrist who was a locum for two years and who wanted a permanent contract but there was none. They are caught up in unnecessary paperwork and more children are then put at risk. That needs to change.

It is important to include every discipline on the team. In my local CAMHS, there was no dietician. There might have been one in another CAMHS but one does not go between the services. One has to stay with the service in one's location. That needs to change.

Access 24 hours a day, seven days a week is very important. I had to take my daughter who is 18 into accident and emergency because she had taken a serious overdose. She had to have an antidote through her arm and sat on a plastic chair for 21 hours while getting it. For three of those hours she was vomiting severely into a bag. She was 17. She should not have been sitting in an adult accident and emergency hospital. These children are vulnerable and it is very hard as a parent to watch that. At one stage they gave me another plastic chair, and then they had to take it away so I had to stand beside her. That is no place for a young person going through a trauma. They are not attempting suicide for attention. They are not well people and they need help and support, not to be put into a more stressful environment. In one of the letters I mentioned, the parents spoke of the relief they felt when they got a letter to say their daughter was on a priority waiting list. They rang their local CAMHS to see what that meant. That means months. Priority should be a couple of weeks. It is such a stressful situation for a parent, watching their child 24 hours a day, seven days a week. It is unfair to the whole family unit. That needs to be reduced to weeks at most. It is unfair to the entire family as a unit. It is too hard. That needs to be reduced to weeks at most. Having the staff numbers required by each team and implementing the recommendations in A Vision for Change will improve all that and remove those waiting lists.

On support for the parents, as chairperson of the carers forum in Dublin city, I have started organising coffee mornings within certain branches. They will extend even further and I hope will be run every month. It is a place where parents can sit down either with me or other parents and where they do not feel isolated. Isolation is a huge factor. It makes any illness very powerful if one feels isolated and one cannot talk about it. Having the opportunity to be around other parents, be able talk freely and not feel as though one is being judged is very important.

Chairman: Yes, definitely.

Ms Sinéad McGee: Another suggestion that should be available on each team is family therapy. Family therapy is very limited and it should be made more available because the family will always be there. The family is the continuity. The therapists we deal with in CAMHS or any other services are a short-term initiative. We are the people who will be there 24-7 from now until whenever, but definitely until into adulthood. That is a very important aspect.

Another concern of mine is the 18 to 25 age bracket. Someone between the ages of 18 and 25 should not have to go into an adult mental health service. It is a daunting experience. My own daughter went into that last year. Something similar to a Youth Aware of Mental Health, YAM, needs to be considered.

Ms Martina Kelly: I agree with everything the other four mothers said. They have made the position very clear and have said more or less what I would like to say.

Chairman: You would endorse all their suggestions.

Ms Martina Kelly: I would endorse everything they have said. I understand and have lived through a lot of that. I believe psychology and psychiatry should not exclude each other. They should work together. We need weekend and night-time help. That is when most traumas happen, but if it is after 5 o'clock in the evening or a Saturday, Sunday or, God forbid, a bank holiday weekend, which happened to us, there is no help available for three days. If a parent is not willing to fight for their child, the child will be lost. All our children are depending on the parents being strong and being prepared to fight for their children because no one else will fight for them.

The child and adolescent mental health services, CAMHS, offered our son a counsellor, which was great. Unfortunately, our son did not take to that particular counsellor. It was not her fault and it was not our son's fault. Some people click, some people do not. He is normally very willing to speak to most people. He likes to talk, but when I asked if there was anyone else he could speak to and said that he would be willing to speak to anyone else, he was not offered anyone. That is at least seven years ago, and he has never been offered anyone else to speak to when he would not speak to that one person. Our families are in crisis. We need serious help, and we need it now.

Chairman: Thank you.

Senator Colette Kelleher: The witnesses have been very clear. Parent support and education are critical, but so also are coffee and chats.

I notice Julie Helen is here. Her mum was involved in writing Informing Families. It is so important that the work that is done is made available. The support groups and the informal sharing of information is critical because if the parents cannot be supported, the child and the young person will not be looked after in the long term.

With regard to the two systems, I would say there are three systems - disability, CAMHS and child protection - and they are all turning in different directions. We need one service for children, and the witnesses have endorsed that. People should not have to go from pillar to post introducing themselves anew only to be told that it is a behavioural problem, not a psychiatric one. How do they make those decisions?

Ms Lauren Keogh: I find what is happening in this regard is that the staff who are working in, say, CAMHS are not trained to identify needs in terms of the disability services and children are being lost. That is very concerning, especially for the staff. They are all about getting funding for their budget. They do not have the correct supports to be able to refer a child to the correct service to get the correct diagnosis. Early intervention is key.

I wish to add another suggestion to those already made. I refer to coping skills as a proactive measure. Ms McGee mentioned that for those children who have mild mental health difficulties, coping skills could be part of the school curriculum. We should teach the parents to teach the children coping skills. The parents could do it at home and the children could do it once a month in school. From the very start of primary school they would have those skills and not ever need the mental health services. It would reduce the costs from the get-go.

Senator Colette Kelleher: In order that we do not get to the crisis.

Ms Lauren Keogh: Absolutely.

Senator Colette Kelleher: It is very important to highlight family therapy and a move away from medication.

Chairman: If the witnesses agree, I will take questions from three Members: Senators Keith Swanick, our Leader, Jerry Buttimer, and Pádraig Ó Céidigh.

Senator Keith Swanick: I thank Lauren, Paula, Louise, Sinéad and Martina for their contributions. I fully agree with them that they are warriors. This is a fantastic initiative and I fully endorse this public consultation process.

My comments are made not only as a Senator and a general practitioner, GP, but, most importantly, as the dad of two young children. The overwhelming message I get from today's hearing is that all the witnesses' situations reached crisis before anything happened. That shows there is a fundamental flaw in the system. They should not have had to attend accident and emergency departments out of hours with their children, which is what they are - children. My heart goes out to them.

Something that frustrates me greatly working as a GP is that sometimes I am forced to refer vulnerable children to an accident and emergency department to access the services to save their lives. It is as important as referring someone with a heart attack or some other physical disability. That is frustrating. However, GPs do not do it lightly but out of necessity. That is one topic that illustrates a fundamental flaw in the system.

I agree there is an over-reliance on medication. Medication is not always the answer. It is part of the answer but we need to emphasise and concentrate our efforts on psychological support, be it cognitive behavioural therapy, CBT, or whatever. I refer to Zara and her therapeutic horse riding. Another important point is that as medics we rely too much on medication. I want that to be acknowledged.

My heart goes out to Louise and her eldest boy, a 17 year old who found himself in an adult mental health ward as a result of a severe reaction to the loss of his dad. It is a very sad story and disgraceful that he found himself in an adult mental health ward. It emphasises that it is imperative for all Senators to support Senator Freeman's Bill which will amend the current Mental Health Act to make it illegal for young people and children to be placed in adult mental health wards. I would be happy to support that Bill.

It is also worrying that, out of desperation, families are forced to seek private counselling and spend huge sums of money because they cannot access that service through the public health system. That is another example of a failing system.

We need to get away from this crisis management. Do the witnesses believe that more investment in community-based services in the primary care setting might help alleviate the situations they described, for example, providing all these services in primary care centres? We hear a lot of talk about primary care centres. I always say that primary care centres are not just about the bricks and mortar but the activity that happens within the centres. This is an open question and is not to anyone in particular. Do the witnesses believe that more investment in that sector could help prevent the crisis management we see taking place?

Senator Pádraig Ó Céidigh: I thank the witnesses for coming to the committee. A number of Senators have been in the House for about one year and this is the most profound sitting I have attended. I extend a special thanks to Senator Joan Freeman for really opening our eyes. We need to shine a big light on this issue. A first cousin of mine committed suicide some years ago, but it still did not dawn on me well enough until Senator Freeman shared her experiences. The representatives present are warriors and they are great people. These Houses and this country has let them down, but with people such as Senator Freeman, however, and with the inspiration given by her and the others in the room today, please God it will not happen for much longer.

I have a couple of questions. Senator Kelleher had some very good and focused questions on where we should go from here. The representatives' views in this regard are very helpful. Moving on from here and following on from a comment by Senator Devine, where are the fathers and what are the roles of the fathers? I know that Louise's partner has passed away. I realised from this that something can be triggered in the mind. A person's mind is triggered and he or she goes off in a particular direction and into a deep hole. That person feels that no one can pull him or her out from the deep hole. That was a learning curve for me and it is very important. The role of fathers in all this is one aspect, other than in Louise's situation, understandably.

I was struck by how long people have been waiting for an assessment or the results of an assessment. People go for their assessments and then nothing happens. One part of the situation is that the system is badly broken, and the witnesses have suggested how we might look at repairing the system. The other part of the situation is that we do not have a system and there is no joined-up thinking whatsoever. I will get to my questions.

Ms Martina Kelly: I endorse Senator Ó Céidigh's comments. There is no joined-up thinking. A person is either in a particular bracket and no one seems to pull together. There is a serious lack of joined-up thinking.

Senator Pádraig Ó Céidigh: But for the parents' strength as individuals and that of their families, things would have been different for them. I am not saying maybe. They would have been different. They were left on their own and isolated. I am delighted to see the Minister of State showing her commitment, which I know is 100% genuine, in making sure we help in future. With regard to the roles of fathers, what can we do for early intervention? I used to teach, and teachers are not qualified in this space. They can share some information but they are not qualified in this respect. I was delighted that reference was made to gardaí and how they help. There has, unfortunately, been a lot of bad press about the Garda.

Ms Martina Kelly: We would have been lost without the Garda.

Senator Pádraig Ó Céidigh: It important to acknowledge and highlight that members of the force are doing enormous and fantastic work, in this and other areas. Gardaí, however, can only do so much. What can be done to get at this early? I am very involved in the GAA and it is a huge issue within GAA and sport. There are people who play hurling, football, soccer and rugby who are challenged with this but have not yet got to the extremes that Louise and the other parents have shared with us about their families. What can be done regarding early intervention? These are my two questions.

Senator Jerry Buttimer: I thank, welcome and pay tribute to all the parents for making the sacrifice to be here and, as Senator Kelleher has said, for baring their souls and sharing their stories. It is not easy to do that.

I am struck by three things. There is no joined-up thinking or uniformity of approach, as Senator Ó Céidigh has said. Let us consider having to engage with a different psychiatrist or psychologist on every visit. For adults that would be bad enough, but it is harder for a young and vulnerable teenager or child who is trying to develop trust or a relationship. My first query relates to the issue of joined-up thinking. I listened to the comments about Tusla and CAMHS. What should we do in respect of having joined-up thinking?

My next question is around funding. In the 2017 HSE budget, €853.1 million is allocated to mental health, a 3% increase from 2016. It is 6.1% of the budget. If parents, those who need, use, depend upon and co-exist with the system, have a blank canvas, how do we spend that money? I am conscious that Lauren spoke of waste in the system. What should we spend that money on?

I have read the presentations and heard the powerful and moving testimony of the witnesses here today. Given that we have created Tusla, the child and family agency, and we have CAMHS, what should the committee tell Tusla and CAMHS arising from today's meeting?

My final question is in the context of Senator Freeman's Bill. I listened to Louise's story. When I attended college, I worked as a porter in Cork University Hospital. I have also volunteered with different disability organisations. Cork University Hospital has a wonderful new facility, built in place of the older ground floor facility, that I hope can offer hope to people. Notwithstanding what Louise has said, and we all agree that young people should not be admitted to adult units, there is a view that the legislation, if it is enacted, will do more harm than good. Would the parents be in favour of any flexibility in that type of situation? If a young person, for example, was to present at an emergency department and no bed was available in the child facility, would there be flexibility? I am conscious of Louise's situation and I fully understand what she did. She did what any mother would do. Her bravery should be commended today. I am not patronising. I am being honest because I know people in similar situations. Given Louise's experience, when she was at her most desperate, should there be that flexibility around admissions?

I thank the parents so much. I know it was not easy for them to come here today. The eyes of the nation are watching. They have given us not just information but also hope. It is, as Senator Kelleher has said, about people. Equally, if it can assist one other person to tell their story, then they have done a huge job.

Chairman: Who among the witnesses would like to address those questions?

Ms Louise Walsh: I will take the question about flexibility of admitting children to adult wards. I would most definitely say “No”. There are enough empty rooms and enough empty beds in our hospitals. An agency nurse could be put in a different room in each hospital. My son was around alcoholics and drug addicts etc. I do not mean to label anyone else in society but if a child feels at his or her lowest, feels worthless, useless and that society and their families are better without them, it is difficult if the child is placed in an adult ward. My son came out of there believing this was what he was. He believed his future was to be the same as the adults with all those mental health problems. The only thing he got from that was a firm belief that this was going to be him in ten years if he did not manage to commit suicide in the meantime. I firmly believe that putting him in there caused more damage. One would not put a child with a kidney infection, particularly a little girl, in a ward with old men. With do disrespect to men, children with mental health issues should not be put in a ward with old men?

These children, whether physically or mentally ill, are sick children and they deserve to be treated in the same way as a child with gallstones or anything else would be treated. They deserve to be treated fairly. They have done nothing wrong. They are blameless. They did not ask for their illness and they need to be treated in the same way as every other child, namely, in a paediatric ward, where there are lovely paintings on the walls and balloons and toys in the corridors outside them. My son was surrounded by alcoholics and other people who were a danger to him and themselves. Under no circumstances would I say there is any excuse for doing that to a child.

Ms Lauren Keogh: I am also on the autistic spectrum. I was only diagnosed at 21, after Zara was diagnosed. When I was 21, I was placed in an adult psychiatric ward on the basis that I was bipolar. At the time, I could not communicate emotions because I did not understand them. It was the worst place for me at 21 years old, never mind a child as vulnerable as the children about whom we are speaking. I agree with what has been said in this regard.

In regard to waste, the question on the community centre and Senator Buttimer’s question on how money is spent, including the 3% increase in 2016, in December 2013, the then Taoiseach, Deputy Enda Kenny, on a visit to Japan visited Toyota to learn about Lean methodology, which for those who are not familiar with it is a programme related to eliminating waste, adding value and keeping in processes only those things that add value or have to be in place for compliance. None of the information he got from Toyota has been introduced here. Why not? In terms of our service, we adhere to lean methodology in terms of the elimination of waste. This will not happen over night there can be a lot of quick wins. We can make a difference by eliminating waste but to do that we need full staff. If all we have is a repeat of stories from one member of staff to another that is a waste of resources. There is a lot of waste, in respect of which I have many ideas but that would take all day.

In regard to Deputy Ó Céidigh’s question on where the fathers are and their role, my husband is in the Visitors Gallery. He has been my rock. He has taken a lot of the abuse that I have taken from our daughter during her challenging times, which she tries extremely hard to control. My husband works full time and he tries to attend meetings. It is very difficult. Without him I would not be as capable of advocating as I am today.

Chairman: Would any of the other witnesses like to respond to those questions?

Ms Paula Dalton: In terms of early intervention, it is important this happens at the point when issues first arise. At seven years old Rhys was presenting with issues not typical in autism. I could see the problem was escalating but when I requested intervention nobody listened.

At that point he needed early intervention in the form of play therapy, which works well for him, and psychological and psychiatric therapy. If interventions are made at an early stage it helps to fix a problem before a child feels his or her life is over or ruined and thus one does not have to spend as much money and resources on the child at a later stage. Art therapies and other similar therapies should be introduced because not only autistic children but all children respond well to visual therapies. It is important intervention centres are child friendly. I know from parents whose children are not autistic but are in need of intervention therapies that children are scared of going to these places if they do not appear child friendly. They either shut down or they put brave faces on and pretend everything is okay but when they go home they have episodes and breakdowns. Without early intervention a child's condition will escalate and become a greater problem.

Chairman: Have all of Senator Buttimer's questions been answered?

Senator Jerry Buttimer: In the witnesses opinion on what or to where should money be directed? We are spending money but as pointed out by Ms Keogh we need to ensure not only that get value for money but that the service provided is intervention rather than reactionary? What specifically would the witnesses like us to bring back to the Minister?

Senator Keith Swanick: It was mentioned that the services in this area are disjointed. What is the view of the witnesses in regard to the primary care element investing more in the community? Would that prevent the type of crisis intervention mentioned?

Ms Sinéad McGee: Yes. I believe more needs to be put into the primary centres to prevent parents and children having to endure the trauma of accident and emergency departments and so that they do not have to wait weeks or months to access services. If a child is taken to see a GP and is determined to be in difficulty he or she should get an appointment straight away rather than having to wait months for it. This is important to a child who is feeling low and also his or her main care-giver. When my daughter was ill, I kept my head above water and tried to remain brave and strong but it broke my heart that she was on a waiting list for treatment. Access to quick treatment and help and support, including for parents to empower them to help their children, is key. It will help to keep young people out of accident and emergency departments.

I also believe that a young person should never be put into an adult psychiatric ward. Having to bring my daughter who is 17 years old to the accident and emergency department of an adult hospital was disgusting. It was so unfair. These children are so vulnerable. Consideration should be given to Temple Street being responsible for children up to 18 years of age. This would ensure they are treated in a protective environment. I agree that there is a need for the introduction of a young adults mental health service because up to 25 people are still going through a transition. They could be trying to settle into college or a new job but they are still trying to discover who they are. While the adult mental health service is excellent, these people find it difficult to engage with a service that caters for people aged 30 years upwards. It is a very different environment. We are supposed to be helping young people to live their lives as best they can.

Ms Louise Walsh: On the question regarding primary care, I believe primary care is the way to go because as children attend primary care centres for dental and physiotherapy services and so on they would not be stepping out of their comfort zone and would see going to such a centre to see a counsellor as normal. They would not feel isolated or have the label of having mental health problems. They would just be seeing the counsellor with all the other kids from their school with appointments. It would be an easier way for a child to get help. My son had

very severe difficulty going to a counsellor. He would not go when we had appointments made and he just told me he was not able to speak to a counsellor. He was not at the stage he could do that. Perhaps if he had been, he would not have been in such a crisis. It is very hard even for adults to go to see a counsellor and it is a tough task. We do not even have to put a name like “counselling” on this. If we put a nice, happy name on it, the child could go to see someone in primary care in a safe environment beside a dentist, for example. This would happen in the community and the person would not go to a hospital or where he or she would be labelled as someone with mental health issues. It is a major fear kids have and they are afraid to say it because people will think they are mad or crazy. It would be something to bridge the gap, a little stepping stone between being a normal Joe Soap and someone who ends up in an acute psychiatric ward. Primary care is definitely the way to go.

Ms Sinéad McGee: I still remember the parents who contacted me with a four or five year old with concerns about their children having suicidal thoughts. There is nowhere for them to go. The child and adolescent mental health services, CAMHS, is directed more at teenage years. We must look at that. There are children aged eight, nine and ten who are affected. We need some support for all them. We should not be saying that people are too young. If they are having suicidal thoughts, they are not too young and they need help.

Senator Joan Freeman: To follow up Senator Buttimer’s statement, he asked the ladies how would they spend the money in question. He mentioned a figure of approximately €150 million or €160 million as a budget for mental health. I am not quite sure of the number but 6% is spent on children. In effect, we are talking about €50 million for 23% of the population that attends mental health services. We are talking about 55 psychiatrists for 1.23 million children. The question is if the witnesses had €50 million, where would they spend it?

As I stated earlier, we have had reports on children and we have heard from expert groups. The witnesses are experts but have they been asked for a response to any of the questions being discussed today? If I said the witnesses are the experts on the issues affecting the children of this nation, can I ask whether they had any idea before they went through this what was going on in our country? I would be interested to hear the answer to that.

Senator Máire Devine: I will go back to the idea of integrated care and placing it within our communities in order that it is normalised and not stigmatised. The creeping professionalisation of specialisms has taken place in the past 25 years and it serves the professional rather than the people. People cannot see beyond their own silo. There is hope in that the Health Service Executive agreed recently to a dual diagnosis programme. I know it is for adults but it is to treat mental health and substance abuse issues together. It is a no-brainer. It is very sexy to be seen as a specialist in something when we need to be able to take a child and look at every aspect. We should be able to look at the psychology of the case and determine the approach that is needed. It is important to get away from the professionalisation of each different strand of what we need in our community.

Ms Martina Kelly: In our case, most of the crises occurred on weekends and nights. The service should be like a hospital in that the personnel should be on call like nurses and doctors. We should have helpers available 24 hours per day, seven days per week. It is terrible that after 5 p.m. every day or on long bank holiday weekends, there is no one to help us bar the Garda. Its members are not trained for this, although they do their best, and we are very lucky with our local gardaí. I give them great praise for the help they have given to my family. It is not fair that gardaí are called into these cases. One evening we were desperate, but as we are from a rural area, the local gardaí were not working and town gardaí who did not know us were called in.

A big van arrived with six gardaí with flak jackets jumped out. One would have thought there was a hostage situation because our son was having a meltdown and had taken every tablet from our medicine cabinet. They were non-prescription drugs but they were Anadin and Panadol, for example. He swallowed the lot and we did not know who to call. I thought we would get the local gardaí but the call went straight to the town gardaí. Six of them arrived and jumped out, ready to attack. One might have thought there had been an assault at our home. I had to run out and stop them as the issue would have escalated. I did not know any of the six gardaí but I asked whoever was the calmest and best mediator to come in and speak to our son. The other five stayed outside and did not know what to expect. Within five minutes the entire issue was defused. Instead of calling the ambulance, they brought him to hospital. Things can get out of control very quickly and some people just do not know how to handle such cases. None of us does, and if it is the first time for any of us, we are not trained and do not know what to do. We need weekend and night help.

I only heard recently that CAMHS is only working on 53% of the staff recommended ten years ago by A Vision for Change. If any company was working with 53% of required staff, no one would manage or run a business. We are dealing with lives and mental health. These young people are our future and we need full staffing for services. No one can work with 53% of staff. We definitely need more help in the community in order that there is not the same stigma with mental health. Our teachers were a great help and spotted problems, but teachers are not trained to deal with mental health issues. They should be given more training to deal with basic mental health issues to help children and us. It is about losing the stigma of mental health. No one else is stigmatised because they have cancer or anything else. No one should be stigmatised because of mental health issues either.

Ms Sinéad McGee: If a child breaks a leg, he or she is brought to an accident and emergency department for an X-ray and the leg is put in a cast for six weeks. When the cast comes off, the child might need some physiotherapy. It is very black and white and one knows exactly what to do and where one stands. With mental health issues, that is not the case. With many young people I have come across, the problem is hidden and they are not shouting out that they will hurt themselves. They do it. We might see them vomiting and wonder about it but they have already acted. Primary care is so important. One should be able to go to a GP and be referred to primary care, regardless of age. It should not matter. If a person is having suicidal or self-harming thoughts and is not in a good place, it is the time to get help. We should not wait until these young people do something. We should look to prevention of a long road being taken in mental health services.

I hate hearing about waiting lists and we have heard of the struggles of parents here and the ones I have spoken to. I hate hearing that a young person is not well but is on a waiting list. It fills me up every time as it is so wrong. There is a staffing problem as well. I attend the management meeting for the Dublin north county and city CAMHS and they do everything. They have worked so hard and put so much effort in but they only have whatever resources they have. They do not want people on waiting lists and they want to be able to take people in straight away, but there are no resources for that. That must be examined. The other part is that staffing should not be all locums and temporary staff. If they have completed their trial period, they should be made permanent. That would provide continuity for the young person and for us, so that we are not going in and meeting a brand new therapist every time. With every new therapist, our children have to start all over again and go through their story from day one, where they have been, how they got here - it is just very unfair. It is for young people. Let us try to get them out of the mental health services and onto the road to recovery. Primary care is

definitely the way to go. We need to put a lot of resources and money into it.

Ms Louise Walsh: As regards how I would spend the money, to be perfectly honest, the way the HSE and health service is at the moment, we are losing all our staff. It is happening everywhere. In Waterford, we have the cardiac care problem. We have no resources. No one in their right mind would stay working in the HSE. Unless wages are increased, we are going to lose the best people. No one would stay working in a hospital that is understaffed, where there is a lack of resources and staff are not appreciated, when it is possible to go private and get paid probably twice as much with better conditions. That is happening across the board in Ireland at the moment with our nurses, doctors and everyone.

It is not a case of just going out and hiring all these people. We have to treat people properly or they will not come to work in the system. That is my view of the underlying problem. We are not paying people enough. I would increase people's wages so they can work in our health system and do the job they went to college to train for and be paid properly. They should not be falling asleep on their feet because they are stretched to the limit. I see it myself working in the public service. I would say the bill across the public service for people going out on stress-related illness is going to be colossal because there are not enough people working across the board. That has to be changed before we can get the proper people in to work in mental health or anywhere else. That is where I would spend the money.

Senator Freeman asked if we had any idea of what was going on beforehand. I was shocked and disgusted and felt very let down. I think more was spent advertising mental health services than providing them. I sat all night and watched those advertisements on television. There was nothing there.

I wrote to the head of the HSE in the south east area. I told him what had happened, and how many times we had tried to access resources. I had phoned CAMHS the week before my son ended up in the adult ward and told them that he was really bad. We had an appointment for the following Monday and I asked them to bring forward his appointment. They told me no, we had an appointment and we had to wait for it and that was that. They did not have the resources to give him another appointment. I turned up on Monday. I left the psychiatric ward and went over for his appointment. I said, "Here I am. My son is over there in the acute psychiatric ward and will not attend his appointment today." That is the service I got.

When I wrote to the head of the HSE, the reply I got was a list of all the resources available - Squashy Couch, the TYRE Garda youth diversion project, all these wonderful places where I could have brought my son. When a child is in crisis and is trying to get a knife in the kitchen to kill himself, a parent cannot say "come on, let us head off and we will go to Squashy Couch or another place and we will have a little chat about your problems". That is not the answer. The HSE tried to justify it by telling me the services were there and I did not access them. I tried really hard to access the services. Our doctor tried really hard to get us in. We turned up three times in the accident and emergency department trying to skip the waiting list for CAMHS. The resources are not there.

I would be very slow to recommend to anybody that they go through the HSE with their children's mental health. I would tell them to beg, borrow and steal to get the money to go private, to pay a counsellor because they are gambling with their child's life if they go through this system. The child might come out alive or he or she might not. That is the reality of things for parents. It just should not be happening in this day and age. It is an absolute disgrace. We give out about waiting lists everywhere but people are going to die. It is down to a flip of a coin

whether a child makes it out of it.

I had no idea how bad things were. If I had not gone through it, I would think the other witnesses here were all exaggerating. I genuinely would think they were just looking for a bit of drama. We are all strong people. There are people who are not as strong as us who are visiting graves and that is reality. It is time that Ireland woke up and did something about this and stopped talking about it. Put in the measures. There are empty beds all over the country - start using them. Open them up and put staff in place so that children can come in.

We should not have to rely on charities or people's goodness and kindness of heart. I am going to Kilimanjaro on Monday for Pieta House. We have raised nearly €160,000. I am not saying this because of Senator Freeman. I am leaving my children for nearly two weeks. In my family and my home, we have raised enough money to save eight lives. I have raised over €8,000 because of people's goodness. I should not have to do that. I should not have to take unpaid charitable leave from my job to go out there to make sure that no family goes through this again. It is not fair and we should not be asking it. I should not be going cap in hand begging the people of my town to give money to save lives.

Chairman: I am going to hear from two more witnesses. Did Senator Swanick have a brief point he wanted to add?

Senator Keith Swanick: I totally agree with Ms Walsh's assessment of resources. When I see a child who is depressed, if he or she is not actively suicidal and I refer them to CAMHS, I would have no problem with him or her waiting four weeks or whatever to be assessed. However, there needs to be a crisis helpline for health professionals whereby, if the child is actively suicidal, there are ring-fenced appointments to ensure that the child is assessed within 24 hours. We need to redirect resources into that. It is not something one would be using very often but when one needs to use it, it should be there - a crisis phone line for health professionals which facilitates kids being assessed within 24 hours in a crisis situation, providing ring-fenced appointments to be used in cases of emergency.

Ms Paula Dalton: In respect of saving money, the waiting lists are so long in all areas in the HSE, even for assessments of need, AONs, and early intervention. They are outsourcing health. They should employ people because they are paying so much more for outsourcing. They are wasting really good money that could be put to use in the mental health services. That is going on daily in every county. I recently realised how much of it is going on in Waterford and I was shocked. That is good money they are throwing away. I do not mean the money they are spending on assessing the children. If they would hire someone instead of outsourcing, they would save money in the long run.

Again in the hospitals, staff are not getting paid enough. I agree they should be paid more. We would have people willing to come and work. I found out recently that in our local hospital, there was a huge shortfall of psychiatric nurses because they just left. They did not want to work in those conditions.

To answer Senator Freeman's question, I knew the situation was a little bit severe as regards mental health but I had no idea how bad it was. I do not think people understand until they are going through it. Much more awareness needs to be raised. We need to highlight this. I did not know, so how would anyone else know? It is the vulnerable people who are suffering. We need people to be more aware and we need to teach everyone. For my neighbour, everything is alright at the moment but she does not know that in two years' time, maybe, her daughter will

not be bullied. There is no knowing. The numbers are increasing. More and more children need help, particularly in Dublin. More money will be needed to help these children if a solution is not found because the number of them needing help keeps increasing.

Ms Lauren Keogh: I will try to keep my remarks concise. I totally agree with Ms Dalton that outsourcing is a huge expense compared to employing a fully-staffed team to deal with the backlog. The money could be pumped it into early intervention. The problem is that there are barely any resources for early intervention and that is leading to a crisis situation. We need to be proactive, not reactive. As I mentioned, there should be investment into teaching children and parents how to implement coping skills. It is easy to sit around talking about it, and all present know what coping skills are, but finding ways to implement them when needed is more difficult.

It is important not to waste time on big ideas. The stuff in the strategic plan for my area for 2017 is so unrealistic. Its first goal is to promote health and well-being as part of everything we do in order that people will be healthier. The third goal is to foster a culture that is honest, compassionate, transparent and accountable. Those goals are currently far out of reach. They need to be realistic. Money needs to go into delivering what people need now, getting the backlog up to date and then looking at how waste can be eliminated. I do not know if any members know about lean six sigma training. As I said, there is a training course in that on Groupon for €26 that could make such a difference to the HSE. It does not have to cost money.

In terms of what should be told to Tusla and CAMHS, the first issue is that they need to be fully staffed, although that is more the function of the HSE. Once that is in place, the organisations need to listen to parents and take accountability. Tusla's child protection function has been shown to be deficient in several cases, with parents providing the only functional child protection. Services need to be interlinked. People cannot be passed from CAMHS to a disability team and then have to wait for another two and a half years. That is not good enough. The lack of interlinked services is creating a crisis.

I knew about mental health services because I had experience of mental health issues as an adult. For children, I have no idea. I thought it was brilliant when we got a letter saying that my daughter had been put on a waiting list because she had anorexia and was suicidal but we were then told there would be a further wait of 18 months. I was not prepared for that. I thought that my daughter would not still be with me in 18 months' time. She had not eaten for four days by the time we went to get this letter saying she was on a priority waiting list. I hope that answers everything. I hope it helps.

Chairman: I thank Ms Keogh. I will now suspend the committee until 2 p.m. unless anyone has a very brief point to add.

Senator Joan Freeman: I invited the witnesses here today. I know it is the Acting Chairman's job to thank them but can I also do so. I am so proud of what they have done this morning. They were absolutely brilliant. Well done to them all.

Chairman: We very sincerely thank the witnesses and all those in the Visitor's Gallery. The Minister had to leave early but we are also very grateful to her for her attendance.

Sitting suspended at 12.35 p.m. and resumed at 2.05 p.m.

Chairman: In this afternoon's session we will hear from advocacy and service providers, as well as from Dr. Geoffrey Shannon, the Government's special rapporteur for child protec-

tion, who will be joining us presently. From BeLonG To, I welcome Mr. John Duffy and Ms Arianna Gallagher; from Inclusion Ireland, I welcome Ms Sarah Lennon and Ms Julie Helen; from Lucena Clinic, I welcome Dr. Maria Migone and Dr. Glenda Kavanagh; from the Children Rights Alliance, I welcome Ms Julie Ahern and Ms Saoirse Brady; from the Irish Society for the Prevention of Cruelty to Children, I welcome Ms Mary Nicholson and Mr. Andrew Jackson; from Mental Health Reform, I welcome Ms Kate Mitchell and Ms Shari McDaid; and from the Psychiatric Nurses Association, I welcome Mr. Peter Hughes. They are all most welcome and I thank them for engaging with the committee on this most important and sensitive topic.

Before we begin, I advise witnesses that by virtue of 17(2)(I) of the Defamation Act 2009 they are protected by absolute privilege in respect of their evidence to the committee. If they are directed by the committee to cease giving evidence on a particular matter and they continue to do so, they are entitled thereafter only to a qualified privilege in respect of their evidence. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given and they are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against a Member of either House, a person outside the House or an official by name or in such a way as to make him or her identifiable. Any opening statements that have been submitted to the committee will be published on its website after the meeting.

I invite Senator Joan Freeman to make a few introductory remarks. I will then invite each witness to make a short presentation to the committee. Time will be of the essence this afternoon. Witnesses may share time with colleagues if they wish to do so. I ask that be indicated in advance. As there will be a large number of witnesses in this session, I ask that presenters keep their opening statements as brief as possible. When the presentations have finished it is hoped there will be time for questions and comments from Senators and responses from the witnesses. With that I call on Senator Freeman.

Senator Joan Freeman: I thank the Cathaoirleach and my fellow Senators. I will just paint a very brief picture of what today is about. We are trying to give the public, but also the Government, a clear picture of what mental health services in Ireland are like on the ground. While it is essential that we do not point the finger at the Government, the HSE or anybody like that, we must still be truthful, honest and fearless about what we are going to say today. Unfortunately and sadly, some people have withdrawn their testimony and refuse to be witnesses because of fear for their jobs. It is therefore very important that we speak the truth today. I ask the witnesses to tell us what it is like for them, in whatever sphere they are coming from, to provide a service to the most vulnerable people in our society.

I really appreciate the witnesses being here today. This is going to be recorded. Let us get what life is really like on the record.

Mr. John Duffy: I thank the Chairman and committee for inviting BeLonG To to attend today. We are always happy to contribute to proceedings which can have a positive impact on the lives of the young people with whom we work. I thank the committee for making it possible for a young person from our service, Ms Arianna Gallagher, to speak today as we in BeLonG To feel that it is extremely important to hear directly from the young people with whom we work and to give them an opportunity to share their voices on issues such as this.

Before I move onto the substance of my presentation, I would like to share a few things about the organisation I am representing today. BeLonG To is a national lesbian, gay, bisexual, transgender and non-binary, LGBT youth organisation. Our service is based here in Dublin but

we also provide services across the country, which are vital supports for LGBT+ youth, including in the area of mental health. We work with many Departments and other partners in order that Ireland's LGBT young people may live in a place where they are equal, safe and valued in the diversity of their identities and experiences.

To achieve this vision we work with LGBT+ young people as equals in the context of three broad pillars. The first pillar is the youth services which we provide through groups in which our youth workers work with young people on the basis of equal partnership. The second pillar is about changing attitudes through our campaigns in support of young people being themselves and through giving them opportunities to talk about the lives and settings of themselves and their peers, such as the opportunity Ms Gallagher will have today. The final pillar relates to research which enables us to shed light on the lived reality of what it is like to be a young LGBT+ person in Ireland today.

I will now share some statistics which are pertinent to today's discussions. These come from a 2016 report by Dr. Agnes Higgins *et al.* entitled "The LGBTIreland Report: national study of the mental health and wellbeing of lesbian, gay, bisexual, transgender and intersex people in Ireland". This study was commissioned in part by BeLonG To and was funded by the HSE National Office for Suicide Prevention. This study raised a number of key issues in respect of LGBT+ youth. First, it reinforced previous research which indicated the most common age for LGBT+ young people to become aware of their identities is 12, regardless of whether that identity is transgender or lesbian, gay or bisexual. The most common age at which to come out was 16. With respect to coming out, this represents a drop of one year in the average since the previous large-scale national study of lesbian, gay and bisexual people, which was carried out in 2009. In respect of that period between 12 and 16 there is concern about how young people are coping with their identity and how they are beginning to accept it. Having to hide that significant part of themselves from others can cause some difficulty, particularly with regard to mental health.

Despite the encouraging fact that young people are coming out at an earlier age, there are still many difficulties which LGBT+ people can encounter in Irish society. According to the research, 50% of LGBT+ students have personally experienced anti-LGBT bullying within their schools. Those that had experienced bullying had higher levels of depression, anxiety, stress and alcohol use. They were also 12% more likely to self-harm and 19% more likely to have attempted suicide. In comparison with the general youth population, LGBT+ young people had twice the level of self-harm overall, so we are looking at something like 56% of LGBT young people aged 14 to 18 having self-harmed. They also had three times the level of attempted suicide, which equates to approximately one in three 14 to 18 year olds, which is again quite a shocking statistic. They also had four times the level of severe or extremely severe stress, anxiety and depression.

Dr. Mary McAleese, in launching the LGBTIreland report, said:

this scholarly report is as essential and revealing as it is horrifying. The ongoing damage is undeniable. That it involves so many young people is tragic. That it is soluble is the good news.

I would like to echo these words today, as the issues that LGBT+ young people face do have solutions. We in BeLonG To have been working with partner organisations such as Jigsaw in the delivery of LGBT+ mental health training to professionals and with Pieta House in the provision of an in-house counselling service to LGBT+ young people who are experiencing

issues around self-harm and suicidal ideation. We are very grateful for their support.

There are, however, many issues which need to be resolved. Ms Arianna Gallagher, who is 15 and who has been in our service since last year, will now speak on some of the issues which young people who access our services face directly and the ways in which we, as an organisation, try to support them.

Ms Arianna Gallagher: As young people who identify as lesbian, gay, bisexual or transgender, we are often dismissed by adults who say that we are only children and that we do not yet know what we are. No one knows oneself better than oneself. When we are disregarded and told that we cannot be this or that and that we must wait until we are older it can be very damaging to our mental health. Even sometimes when we go to counselling services, for example, we may be told the same thing by adults who are supposed to be trained in these fields. When we go to places such as BeLonG To, however - which has been of extreme benefit not only to myself but to hundreds of people who identify as LGBTI across the country - we are asked what name and pronouns we prefer and we are respected as equals. There is no sense of them being adults and us being children. We are respected. People are referred to and spoken about as they wish to be and they are not judged for it. We are surrounded by people who are in similar situations to ourselves and adults who have gone through similar situations and who respect us just as much.

The different BeLonG To groups such as BeLonG To Sunday, BeLonG To Individuality and BeLonG To Ladybirds help different groups within the LGBT community. The partnership which BeLonG To has with services such as Pieta House has also been of extreme benefit to the mental health of young LGBTQ people. They know they have a place to which they can go where, if they share their problems from home or school whether about bullying or about something else, they will be respected and listened to and will not be turned away like they might be from other counselling services. BeLonG To has seriously improved my mental health and I know for sure that it has helped the lives and improved the moods of hundreds of LGBT people across the country. The number of teenagers walking at the front of the parade during the recent Pride festival just goes to show how proud we have become because we have something like BeLonG To, which teaches us that we can be proud to be who we are, that we should not be afraid to be who we are and that we should just be who we are without being afraid. Without BeLonG To, the mental health of the young LGBTQ population across the country would be a lot worse than it is at the moment because some of us live in areas where, let us say, it is still not accepted, or we go to schools where we would still get bullied over it. We need BeLonG To not only here in Dublin and in other counties but across the country. Every single county should have its own service like BeLonG To in order that those who live in remoter areas do not have to travel far to be who they are. There should be a right to be who you are and to be respected for who you are.

Chairman: I thank Ms Gallagher for her contribution and for being brief as well. I invite Ms Sarah Lennon from Inclusion Ireland to make her contribution and I ask her to be as brief.

Ms Sarah Lennon: I thank the committee for the invitation to speak here today. I will share my time with my colleague, Ms Julie Helen. As the Chairman said at the start, it is a very important topic.

Inclusion Ireland is a national, rights-based advocacy organisation that works to promote the rights of people with intellectual disabilities. Our work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy. Intellectual disability involves a greater than average difficulty in learning. A person is considered to have an intellectual dis-

ability if their intellectual functioning is below average but also their adaptive skills may be below average and the condition is present from childhood. Childhood is particularly important for people with intellectual disability.

Through our advocacy work and community engagement we have contact with people with intellectual disabilities and their family advocates on a daily basis and from all across the country. We know that people with intellectual disabilities experience a higher instance of mental health difficulties than the general population. There is much supposition and reasons out there as to why that might be the case but we know that people with intellectual disability are more likely to have difficulty with their mental health than the general population. As recently as 2015, the Health Services Executive estimated that 25% of people with mild or moderate intellectual disabilities also experience mental health difficulties and if behavioural difficulties are included then up to 50% of people can experience that diagnosis. As members can appreciate, that is a large number of children and adolescents.

The recent Health Research Board, HRB, statistics show that 35% of all people with intellectual disability are between zero and 19. In a moment, my colleague, Ms Julie Helen, will talk about our community engagement work and some of the case studies that we have encountered. I am aware that we use a lot of statistics and it is nice to be able to colour it with some case studies from the ground.

A Vision for Change has been set out but both the National Disability Authority and the Irish College of Psychiatrists have commented upon the fact that people with intellectual disabilities experiencing mental illness do not have their needs adequately met. A Vision for Change is not new but it sets out a clear structure for how mental health services for children and adolescents who have an intellectual disability should be delivered. In the policy's recommendations, children and adolescents with a diagnosis of mild intellectual disability should be seen in mainstream child and adolescent mental health services, CAMHS. Children and adults with moderate to severe intellectual disability - that is not language we tend to use but they are the terms set out in the policy - should be seen by one of 15 mental health and intellectual disability, MHID, teams across the country. We will see from the case studies what the experience is like on the ground, and what the mainstream experience has been for people as well.

Our efforts prior to the meeting to find up-to-date information on how many MHID teams have actually been established proved fruitless. I do not know what the experience of other witnesses has been in that regard. There is evidence that the numbers of teams is far below the recommended number in A Vision for Change. In 2015 the Mental Health Commission reported that 12.95 adult MHID posts were under the auspices of or funded by the HSE. Approximately 300 posts for adult MHID and 150 MHID posts for children and adolescents were recommended for child and adolescent mental health services in A Vision for Change.

The United Nations Convention on the Rights of Persons with Disabilities has an article devoted to children which states "States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children." Similarly, Article 25 states "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability." It is clear that were Ireland to ratify the convention, it would not be in compliance with these articles. That is another one to add to the list of areas we have identified where we need to be in compliance before we ratify.

The case studies will also illustrate the difficulties that co-morbidity can provide. Where a

child or adolescent has intellectual disability and mental illness there is often no clarity over responsibility. Children with autism are often excluded because anxiety issues are very common for those on the autism spectrum. Those young people then fall through the cracks.

In a broader context there are practical things that can be done to improve the experience of mental health services for everybody, but for people with intellectual disabilities in particular. In Inclusion Ireland we feel very strongly about accessible information. More can be done in that regard. We had a look at the Mental Health Commission's website and while I have a lot of respect for it, the only document in an accessible version on it available to people with intellectual disabilities is from 2010 and it was a code of practice for staff. More could be done such as putting more information about mental health services, mental health tribunals and national standards in an easy-to-read format. It is also important that information is available on how to make a complaint. On that note I will hand over to my colleague, Ms Helen.

Chairman: I thank Ms Lennon. I acknowledge the fact that Ms Helen was present all morning. I invite her to commence her presentation.

Ms Julie Helen: Inclusion Ireland receives many queries for information or support from families of children and adolescents with intellectual disabilities and some of those also have experienced difficulty accessing CAMHS in cases where a mental health difficulty arose. I will now detail some brief case studies so that the committee can get a flavour of our work on the ground with the community engagement team.

A parent in HSE Dublin north east requested the service of CAMHS. Her daughter had self-harmed and had spoken of suicide. CAMHS said it would not take the case as she was almost 17. Adult services would not take the case as the child was not yet 18. It was only due to a threat of a complaint under the Health Act that the child was seen.

The mother of a young boy in HSE Dublin north east required the services of CAMHS. The boy self-harmed and on one occasion had such an episode of self-injuring behaviour that he had to be brought to an accident and emergency department. He was referred to CAMHS, which would not offer him a service as his case was not deemed to be severe enough. After going home, his mother was reduced to begging CAMHS for a social worker.

In separate cases, two teenage boys in HSE Dublin north east both began to engage in seriously challenging behaviour. Their parents were referred to CAMHS, which would not offer either child a service as their intellectual disability was more than mild.

A parent in HSE Dublin mid-Leinster was referred to CAMHS as their 14-year old child was self-harming and had attempted to take their life. CAMHS did not see the child as the case was seen as a disability issue rather than a mental health difficulty. The child was inappropriately referred to the school guidance counsellor for help.

A social worker in HSE west contacted Inclusion Ireland when she referred a young boy of 13 to CAMHS. The boy is out of school due to serious behavioural issues. The professionals with whom the boy is engaged believe that there may be an underlying mental health issue. CAMHS would not take the referral due to age grounds and disability grounds.

A mother in Cork contacted us when she could not get an appointment with CAMHS for her 11-year-old daughter who has anxiety issues and is on the autism spectrum. The family has been waiting for one and a half years for support with the issue.

Services have been approached by families to provide information to young people with intellectual disabilities and mental health issues but there is a lack of accessible information in this area.

Inclusion Ireland has several recommendations that it would like the committee to consider. Our key recommendation is to make sure that children and adolescents with intellectual disabilities are included in its deliberations on mental health. We ask the committee to consider the case studies we have put forward and to consider children with all levels of disability regardless of the label they are given.

The 15 child and adolescent mental health and intellectual disability teams recommended in A Vision for Change need to be put in place and appropriately staffed by professionals with knowledge of both mental health and intellectual disability in order that people can get the support they need when they need it. Clarity is needed on how children with intellectual disabilities and mental health difficulties are dealt with. The pathways need to become clear in order that people know where to turn. We must not forget those with mild intellectual disabilities.

Further support is needed for children and adolescents who have autism spectrum disorder as they too often fall through the cracks. More inter-agency working and joined-up thinking is needed between the child and adolescent mental health services and disability services in order that waiting times can be reduced for children and adolescents.

Accessible information needs to be developed for children and adolescents with intellectual disabilities around how the mental health system works for them. They have a right to information, which could be provided in an easy to read format and plain English.

Chairman: I thank Ms Helen and invite Dr. Migone to make her presentation.

Dr. Maria Migone: I am joined by my colleague, Dr. Glenda Kavanagh, from the Lucena Clinic, which is one of the child and adolescent mental health services, CAMHS, in Dublin. We cover a catchment area with a population of approximately 646,000. Under A Vision for Change, we are supposed to meet the needs of the 2% of children with the most severe mental illness. This includes, among other conditions, children with major mood disorders, psychosis, severe eating disorders and debilitating anxiety disorders. This group of children requires specialist intervention. The purpose of our attendance is to highlight the lack of staff in CAMHS when compared with the recommendations set out in A Vision for Change, the increase in referral numbers to our services and the lack of access to inpatient beds.

The Health Service Executive has indicated that increasing the age of referrals to child and adolescent mental health services to 18 years will increase the works for CAMHS teams by 100% because rates of mental illness in the 16 to 18 years age group are much higher than in younger age groups. The number of presentations to accident and emergency services with self-harm is high, with the highest number in the 15 to 19 years age group. The number of referrals to children's services of young persons with self-harm and suicidal ideas has increased significantly. The recent CAMHS annual report showed that those presenting with self-harm and suicidal ideas accounted for approximately 70% of referrals among children.

The rate of suicide in children in Ireland is also very worrying. Suicide rates for boys are the fourth highest in Europe and the highest in Europe for girls. We should, therefore, prioritise mental health services for people in this age group.

We will cite the example of psychology posts in our service to highlight the staffing diffi-

culties we face. Based on United Kingdom figures, our service should have 63 psychologists. Based on the more conservative figures in *A Vision for Change*, we should have 26 psychologists, whereas we have only 8.6 psychologists. We only refer children for admission to adult units as a last resort and do so very rarely.

We will highlight some of the reasons for the lack of inpatient beds for children and ways in which we could avoid some child inpatient admissions. On the first issue, it is proving difficult to recruit and retain child psychiatrists to work here. Without a consultant, some of the inpatient units have been forced to reduce their numbers by half because other people have had to step in to try to fill the empty posts. The reason is that working conditions in Ireland have been compared unfavourably with those in other English speaking countries. As a result, we are unable to retain senior staff and trainees are moving abroad. In addition, many consultant colleagues in Dublin have left permanent posts in recent years. Others are on long-term sick leave or have chosen to emigrate. If staffing for CAMHS could be improved, we would be better able to retain some of these senior staff.

It is also difficult to recruit and retain nursing staff to work in child and adolescent mental health services, including the inpatient CAMHS units, especially in Dublin. This is leading to beds being closed, which increases the number of children inappropriately ending up in adult mental health units. Some emergency staff are moving to other parts of the country where housing is less expensive. We should adopt the approach taken in other countries and consider ways of attracting staff to live in the capital.

From the point of view of trying to reduce admissions of children aged under 18 years, access to acute day hospitals would allow psychiatrically unwell children to receive more intensive intervention in the community as opposed to being admitted to hospital. While these services require large numbers of staff because they are highly labour intensive, they are a much cheaper option than admitting children to inpatient units. If CAMHS funding was ring-fenced, these services could be developed.

The multidisciplinary staff who work in our teams are dedicated and hard-working. Our service has experienced a significant increase in referrals recently, details of which I submitted to the committee. The number of referrals in the past ten years increased by between 50% and 365% per annum, with no increase in the number of staff on our teams. On the contrary, the number of staff has reduced in some areas. It is very difficult to work in such conditions and we are unable to deliver the service we would like to deliver.

Chairman: I thank Dr. Migone and invite the spokespersons for the Children's Rights Alliance to address the committee.

Ms Saoirse Brady: The Children's Rights Alliance welcomes the opportunity to address the Seanad Public Consultation Committee. The alliance is a national movement uniting more than 100 organisations to make Ireland one of the best places in the world to be a child. We change the lives of all children by making sure their rights are respected and protected in our laws, policies and services.

The Children's Rights Alliance is deeply concerned about the provision of mental health services to children and young people in Ireland. As the previous speaker noted, according to the recent UNICEF report, Ireland has the fourth highest teen suicide rate among high income countries. Recent studies suggest that young people in Ireland may have a higher rate of mental health issues than their peers in other countries. However, this has not resulted in a correlated

level of service provision.

All children have a right to enjoy the highest attainable standard of physical and mental health under Article 24 of the UN Convention on the Rights of the Child. The UN Committee on the Rights of the Child has emphasised the serious nature of mental health problems for children and the need to tackle “behavioural and social issues that undermine children’s mental health, psychosocial wellbeing and emotional development.” In our alliance report card 2017 grading the Government on its progress in 2016, mental health received a grade of D minus, reflecting the lack of progress on realising children’s rights in the area of mental health. Children’s rights should be respected and central to the provision of mental health care.

The Children’s Rights Alliance welcomes the introduction of the Mental Health (Amendment) Bill 2016 which proposes, if passed into law, to introduce a prohibition on the admission of children to adult psychiatric units save in exceptional circumstances where it would be in the best interests of the child to do so. In this regard, the legislation should provide for a comprehensive definition of the term “best interests” and an oversight mechanism to ensure children’s rights are respected. A comprehensive definition of the best interests of the child and the factors to be taken into account are already outlined in the Children and Family Relationships Act 2015. This definition should be considered and adapted for legislation to amend the Mental Health Act. One of the important factors in this regard will be hearing the voice of the child. We will all agree that it was essential to hear from Ms Gallagher today.

As recognised by the Seanad committee, there is a need not only to prevent the admission of children to adult inpatient units but also to address the underlying issues in the child and adolescent mental health services which result in these admissions taking place. Ms Ahern will outline the Children’s Rights Alliance’s views on the waiting lists for CAMHS, the persistent admittance of children to adult inpatient units, the need to develop an out-of-hours service to respond to the needs of children and young people and the introduction of an advocacy service for children and young people.

Ms Julie Ahern: I will first address the waiting lists for child and adolescent mental health services, which are underdeveloped and for which demand continues to exceed availability. Between January and March of this year, a total of 2,818 children were waiting for a first appointment with CAMHS, of whom almost 300 had been waiting more than a year. In 2016, the UN committee examined Ireland and expressed concern about access for children and young people to mental health treatment and about the long waiting lists for support. It recommended that the State act to improve the capacity and quality of mental health services. The Children’s Rights Alliance acknowledges there are significant staff shortages in CAMHS, which we heard about earlier and which contribute to the long waiting lists for children. Of the recommended 127 specialist teams, the most recent figures we could find show 67 CAMHS teams are in operation. Not all of these operate to full capacity and there are significant geographic variances in provision. For example, there are no services for those aged 17 in north Tipperary because the HSE has not been able to fill a clinician’s post there. Achieving the full staff complement of CAMHS is vital to ensure children and young people are not put at risk by waiting too long for support. Reducing these waiting lists requires ongoing investment in the development of child and adolescent community mental health teams.

The UN Committee on the Rights of the Child clearly states that where placement in a psychiatric unit is necessary children should be separated from adults where appropriate. It emphasises that any decisions on their care should be made in accordance with their best interests. In 2016, the committee expressed concern at the ongoing practice of admitting children and young

people to adult wards due to the lack of suitable age appropriate facilities. It recommended the State take action to address the issue by improving the capacity and quality of services for inpatient treatment. The Mental Health Act 2001 is outdated and not in line with Ireland's international human rights obligations, particularly those relating to children. The Act does not require children and young people to be admitted to age-appropriate facilities. As a result, we all know children and young people are placed in adult facilities. In 2016, some 17.8% of all admissions of children under the age of 18 were to adult units. The mental health commission's code of practice states the placement of children in adult wards should be phased out by the end of 2011, but it is very clear this non-legally binding code has not been effective. There is an overall shortage of inpatient beds, and existing beds are not always used to full capacity. As we have heard, A Vision for Change recommended 108 beds should be operational throughout the country. However, at the start of the year, only 66 beds were in operation and since then we have seen a 50% reduction in state-of-the-art facilities such as Linn Dara in Cherry Orchard. These have been due to staffing issues. The 2013 report by the Inspector of Mental Health Services showed children are placed in adult facilities even when adolescent beds are available. Investment and support is needed to ensure all adolescent inpatient beds are available and used and units are fully staffed. Investment in primary care services and the establishment of emergency out of hours community support are also necessary.

I will briefly address the issue of advocacy services for children and young people. An independent advocacy and information service exists for adults in mental health difficulties, but there is no equivalent national independent service for those aged under 18, particularly those using inpatient services. This means children cannot access their right to information, their right to be heard and their right to participate fully as service users in mental health services. The UN committee has recommended establishing a mental health advocacy service for children that is accessible and child friendly. We echo this recommendation and call for the establishment of a national independent advocacy service for all children under the age of 18 engaged in mental health services. I thank the committee for its attention, and I am happy to take questions afterwards.

Ms Mary Nicholson: I thank the committee. I watched some of the parents who gave evidence this morning and who spoke about their experiences. If that is not compelling, I do not know what is. What would be really good is if we heard from more young people, such as Ms Gallagher. This is about children and young people and hearing their voices in the process would be beneficial.

The ISPCC is the national child protection charity. We hear from children every day and we will base our evidence today on this. We have 1,000 contacts from children every day through our Childline service. Last year, we received more than 15,000 calls and 3,000 online contacts on mental health issues. These were on everything from self-harm to bullying to sexuality to identity. They are huge issues for children and young people. Very often we are a first port of call because we are a 24 hour listening service that is directly accessible to children and young people and available nationwide. Everything we will say will be based on what they tell us on a daily basis.

A big issue, which echoes what many people have already said, is excessive waiting lists. Young people and their parents seek support, but when they reach out this support is sometimes not available for 12 to 18 months. They and their parents call us and they are frustrated. They are at the end of their tether. They are trying to find something while they are waiting for the mental health service. This brings up something Mr. Jackson will speak about, which is the

importance of prevention and early intervention. Not every child needs CAMHS. Many other services can be used to support children and young people, and if we get in there early it will stop some children from having to go to CAMHS, which will free up time and reduce waiting lists.

Children may have a dual diagnosis with mental health difficulties and addiction issues. One young person was told to come back at the age of 18 because there was no service for 17 year olds. Her father resorted to detoxing her himself in the house because no service was available and he was at the end of his tether. This was the only option available to him at that point. This is something we need to look at. The services should be needs-led and they should meet the needs of children and young people, wherever they are.

Ms Ahern spoke about the out of hours issue. A total of 75% of calls received by the ISPCCC Childline service come through out of hours. People need support out of hours. Dr. Jeffrey Shannon's recent report on section 12 echoed this and found 75% of cases were out of hours. Not all of them were mental health cases by any means, but some of them certainly were. It indicates a need for services outside the hours of 9 a.m. to 5 p.m. from Monday to Friday. We know childhood and children's issues happen 24 hours a day seven days a week.

Hearing the voice of the child is important and people have spoken about this. The children we have spoken to have told us they do not feel listened to. They are frustrated their cases are discussed with their parents but the information is not shared with them. Children who are 16 or 17 years old can access medical care in their own right, but it is ambiguous as to whether the mental health aspect can be looked at in this regard.

Another issue is placing children in adult psychiatric units. Everybody here has said it, so I do not need to go into it again. Children should not have to head outside of the jurisdiction to get the support they need. We have seen a lot of this in recent years. The support should be here. There is a huge amount of expertise. Having to ship off to another country a child who is already vulnerable will exacerbate the situation.

What has come across to us through our support line and our face to face service is parents and carers do not know what to do. They are not supported. They are not sure how to support their young person, what the plan is and who to go to for help. We have a postcode lottery with regard to whether a CAMHS team happens to be in operation and is fully functioning. If this is the case, there have been very positive and good results, but if it is not, because there is not a full team, a child does not necessarily receive the service. If a child receives another service or is not bad enough for CAMHS, parents have expressed frustration that they must go down the private route because support is not available because they do not meet the criteria.

We need to address the waiting lists and consider the importance of prevention and early intervention. We must broaden the referral pathways so more than a GP can make a referral. We must ensure 24 hour support for children experiencing mental health difficulties. Their views must be heard and parents and caregivers need to be supported.

Mr. Andrew Jackson: I will speak briefly about our experience as a service and about prevention and early intervention. The testimony today and what we heard earlier illustrates the level of frustration felt by parents and young people when it comes to accessing services. I could go through anecdotal cases, but there is no need to echo what was said earlier because it was illustrated perfectly. It shows the level of crisis management happening with our services. This relates back to the adage that prevention is always better than cure, which is something that

is very true for mental health services and for services in general which relate to children who might have behavioural or emotional difficulties.

There are a huge amount of service available at the moment, including our own child and family support service, the area-based childhood programme, SPECS. The list is quite long. Often there is a referral issue. People often do not know who to go to, how to be referred or what supports to actually seek. This plays into the frustration levels that parents and young people feel. An informational route needs to be introduced so that everyone knows from a very early stage how to access the correct levels of supports when necessary. The level of public health nursing needs to be massively increased so that once any person becomes a parent for the first time they are well armed with the knowledge of how to access supports if an issue arises. We need to try to get away from the level of crisis management that seems to be dogging the entire system currently. We have heard the statistics from Lucena and from CAMHS. We see the statistics ourselves when we look at our own Childline figures. Tusla does not see itself as a crisis management agency. It sees itself as a preventive agency, although it does deal with crisis management. Within its own founding legislation Tusla states that it is an agency that provides preventive family support services. It is very clearly defined and yet it is dogged with crisis management. That becomes problematic. Tusla's budget is sizeable. The figures thrown about are quite large, but less than 1% of its budget focuses on preventive works. That needs to increase. We need to focus on preventive steps. As my colleague, Ms Nicholson, said, there are many cases which do not need to get to CAMHS. If the correct work is put in at the correct stage we can prevent that so that it does not become overburdened with work that need not have arisen.

When we look at prevention as opposed to crisis management, we also look at the very nature of economies of scale and what investment can really improve. Research completed by the National Economic and Social Forum stated that if Ireland was to invest appropriately, for every €1 it invests in a preventive piece of work its savings would be between €4 and €7 in the outcomes. The cost base analysis is reduced, and that is a massive saving. For every €1 spent we would save between €4 and €7 if we avoid the crisis management work. We need to focus on that preventive piece of work again. If we do not we might end up on the same path as other agencies in other jurisdictions. The American system is particularly bad at focusing on preventive steps. It is very crisis-oriented. For its cost base analysis, it costs the US tax payer \$18, compared to just \$1 of investment if it focused on preventive measures.

Focus needs to be brought back to this prevention and early intervention model. There are many great services out there, including our own, and if we can reduce crisis management - although some crisis management will always happen - crisis management agencies can work successfully and remove the necessary bogged-down status that we seem to be in at the moment.

Dr. Shari McDaid: I thank the committee for inviting Mental Health Reform to appear here this afternoon. I particularly thank Senator Joan Freeman, rapporteur of the committee, for shining a spotlight on this significant matter and facilitating this space for child and youth mental health to be discussed within the Seanad. I also thank our colleague organisations who have appeared before the committee, and to reflect on the consistency that is being provided. Many of the organisations here are members of Mental Health Reform and members of the Children's Mental Health Coalition, which we have provided the secretariat for a number of years. There is a lesson in the consistency of what is being said about what could help. It is not a matter of figuring out what we need to do. It is much more a matter of implementing what we

know needs to be done.

Mental Health Reform is the national coalition of mental health in Ireland, promoting improvement to health services and implementation of our national mental health policy, A Vision for Change. We have 59 member organisations, many of which operate in the area of child and adolescent mental health, including Jigsaw, Spun Out, ISPCC, the Children's Rights Alliance, the Irish Association of Infant Mental Health and the Union of Students of Ireland. We have shared and provided the secretariat of the Children's Mental Health Coalition. The primary object of that coalition has been to advocate for improvements in child and adolescent mental health services. This has been underpinned by evidence-based research and guidance produced by the coalition, including its most recent report on meeting the mental health support needs of children and young people in Ireland. We would be happy to provide copies of same to the members of the committee.

We welcome the opportunity to discuss the experiences of children and young people and their families in accessing mental health services in this country. We understand that this consultation is taking place during a period when the Mental Health (Amendment) Bill 2016 is moving through the legislative process. This legislation is designed to end the practice of admitting children to adult psychiatric units except for in exceptional circumstances. We recognise the positive intention of the Bill. Mental Health Reform and the Children's Mental Health Coalition have long called for an end to inappropriate admissions of children to adult wards, in keeping with the UN Convention on the Rights of the Child. Admission of a child to an adult ward can make the inpatient experience much more distressing for the child, as we in Mental Health Reform have heard when young people speak to us about that experience. It does not always provide a safe environment and it does not provide a place that supports the child's recovery. We see ending inappropriate admissions of children to adult wards as an urgent priority and an urgent policy objective. Fundamentally, what is required in order to make that right realised is the immediate implementation of the resources necessary to provide the community-based and age-appropriate acute care that would reduce child and adolescent admissions to acute adult wards. We have consistently called on the Government to develop early intervention and community-based mental health services and supports for children and young people, and I will address what a community based mental health service would look like.

We have heard about the need for early intervention. In the area of perinatal and infant mental health there is widespread consensus that the perinatal and early years period provides a unique opportunity for the prevention of mental health difficulties, in addition to the fact that early intervention for mental health challenges can happen with mothers and infants at that time. However, perinatal mental health supports remain significantly underdeveloped, and early years infant mental health has received little recognition and little priority in the Irish context. Early intervention needs to include a response which places the emotional health and well-being of mothers, infants and families on a par with that of their physical health. The absence of specific policy and supporting service provision to address such needs is a gap of huge significance that must be addressed as a matter of priority. I would agree with the previous speaker that all the evidence is that when those kind of supports are provided in infancy, huge value of money is achieved, as well as much better outcomes over the lifetime of the child.

In terms of mental health in primary care, Mental Health Reform has recently welcomed the sanctioning of the recruitment of 114 assistant psychologist for primary care teams across Ireland. We hope that those assistant psychologists will be recruited as a matter of urgency. The addition of these posts is a positive step towards providing earlier access to mental health

support for children and adolescents. However, they will not be sufficient on their own, and it is imperative that such efforts by Government continue to increase capacity in mental health in primary care. Mental Health Reform and the Children's Mental Health Coalition have consistently advocated for enhanced capacity within the primary care sector to provide comprehensive mental health services. To date there have been significant shortfalls in this area. We specifically advocate for increasing the availability of mental health expertise through dedicated mental health workers across all primary care teams, who would enable early intervention, and significantly, we believe, reduce the number of referrals required to child and adolescent mental health services. We would like to highlight the need for access to specialist mental health services, and our colleagues in Inclusion Ireland have identified one group of young people and children who need specialist mental health services. It is ironic that the services for the children who are most vulnerable because of having dual or co-occurring conditions, such as mental health and intellectual disability, children and young people with dual diagnosis of mental health and addiction or children with other disabilities, for example, from the deaf communities, have received the least development since publication of A Vision for Change. There are ongoing difficulties in accessing child and adolescent mental health services for these children despite a decrease in the CAMHS waiting list. We heard earlier today that, as of December 2016, approximately 2,419 children and adolescents were waiting to be seen by CAMHS, of whom almost half were waiting more than three months for a first appointment and almost 10% of whom were waiting more than 12 months. Between the end of 2015 and 2016, the number of children waiting more than a year had increased by almost 20%.

The difficulties for children and their families in accessing appropriate mental health care - the lack of community-based mental services - is reflected in the high numbers of child admissions to adult inpatient units. As of December 2016, almost 20% of children were still being admitted to acute adult services and the Ombudsman for Children has reported that a number of complaints submitted to his office were about children, particularly children at risk of suicide or self-harm, being inappropriately placed in adult inpatient facilities and that these situations appear to be due to a lack of suitable emergency placements.

We have previously identified the lack of 24-7 crisis services for children and young people as being particularly problematic and this is reiterated by UNICEF's report card on child well-being, which shows that Ireland has the fourth highest teen suicide rate in the OECD region. In addition, as figures were highlighted earlier, the rates of self-harm show that such practices are highest among young women aged 15 to 19 and among young men aged 20 to 24. Some experts in the area of child and adolescent mental health have pointed out that it is at the very point at which children and adolescents are most at risk that the least amount of provision is available and it is ironic that the point at which we could have the most impact on young people's lives and have the best outcomes for the future is where the least provision is available. We believe that 24-7 crisis mental health services should be made available to children and young people in every community in Ireland as a matter of priority.

We have also identified the challenge of providing high-quality accessible mental health services as a result of the difficulties with inter-agency collaboration. The Children's Mental Health Coalition conducted a small survey of two areas in Ireland and found that a bewildering number of agencies were involved in supporting the mental health of children. Therefore, we advocate for a national level approach to inter-agency collaboration to ensure there is a smooth process through all the myriad of agencies for the child and the family to be able to get the services they need.

Other shortfalls we would like to highlight include the lack of a common assessment framework for children in the care and youth justice systems. Such a common assessment framework would ensure that the mental health needs of children in the care and youth justice system were considered holistically as part of the wider supports that are provided for them.

We would also reiterate here the need for an advocacy service for children and families who are engaged with mental health services or who are trying to get mental health services. In the absence of an advocacy service that is tailored to children who are using mental health services and their family members, there is growing concern that this group of children and young people are not being heard in terms of their experience of the services, their will and preferences with regard to how mental health services are provided.

We agree that the lack of staffing in CAMHS must be contributing to many of the shortfalls in service delivery. As of the end of December 2015, there was just 51.6% of the staffing level recommended in A Vision for Change across child and adolescent mental health services and despite concerted efforts by the HSE to improve staffing levels in CAMHS in the past couple of years, there has been very little increase in the staffing available. In essence, child and adolescent mental health services are in crisis across the country in terms of being able to get adequate skilled staff. For example, there is no consultant psychiatrist in post in Cork at present, which is putting extreme pressure on existing services, in particular, in providing crisis support into the emergency departments in Cork.

Additional measures must be put in place as a matter of urgency to ensure that child and adolescent mental health services are adequately staffed and to look at creative ways of using existing staff to enable prompt access to CAMHS. The increasing demand on an already over-stretched child and adolescent mental health system undoubtedly will continue in the context of an increasing demand from children and their parents for better supports.

Despite recent positive developments, there are still huge challenges to bringing about the type of mental health care for children and young people that fulfils both national policy and international human rights obligations. These challenges reflect the continued vulnerability of children and adolescent mental health services across the country and the need to have sustained political will to improve the mental health outcomes of Ireland's children and young people.

We are happy to answer questions.

Chairman: We will move on to Mr. Peter Hughes of the Psychiatric Nurses Association.

Mr. Peter Hughes: I thank Senator Freeman and the committee for the invitation to appear before it.

The Psychiatric Nurses Association represents the vast majority of nurses working in the mental health services. Unfortunately, the number of nurses working in the CAMHS is diminishing. It is difficult to recruit, particularly in the CAMH services.

I will highlight our concerns regarding the child and adolescent mental health services. The inadequacies and underinvestment in the current provision of CAMH services is something to which my union has consistently drawn attention and today's consultation should help in addressing the many gaps in CAMH services that exist nationwide.

In 2006 the Government policy on mental health, A Vision for Change, was published outlining a ten-year plan for the provision of mental health services. Chapter 10 of that widely

welcomed strategy outlined the recommendations for child and adolescent mental health services. Some of the key recommendations included the provision of two multidisciplinary teams per 100,000 of population, one liaison multidisciplinary team per 300,000 of population and one day hospital per 300,000 of population. It went on to state that urgent attention should be given to the completion of the planned four 20-bed units in Cork, Limerick, Galway and Dublin and that multidisciplinary teams should be provided for these teams. This would have resulted in 100 beds nationally.

Most importantly, the strategy in A Vision for Change included a provision for an evaluation after five years to assess the progress in the delivery of child and adolescent mental health services and whether it is meeting the needs of the population. That did not happen and 11 years on, one must question the commitment to the recommendations in A Vision for Change. The Psychiatric Nurses Association, PNA, in partnership with the Royal College of Surgeons in Ireland, RCSI, published research last year on the implementation of A Vision for Change in the adult mental health services ten years on. The results were stark. Among the findings were that 60% of beds were closed yet only 30% of the recommended community services were put in place, and there were no 24-hour crisis intervention services as recommended.

We are currently conducting a second phase of research in partnership with the RCSI on the specialist elements of A Vision for Change, inclusive of CAMHS. Early indications suggest that 37% of the recommended multidisciplinary teams are operational as outlined in A Vision for Change, most of which do not have a full team, while 53% of the liaison services are in operation. There are now 48 operational beds out of the 100 beds which were recommended. This research will be concluded towards the end of the year.

The population of children nationally is expected to increase by 8,500 between 2016 and 2017, which is consistent with the percentage increase annually over the past decade. This projection, coupled with the expansion of the free GP scheme, will create an additional demand on child and adolescent services. I refer also the appalling situation of young homeless children who currently live in hotels, guest houses and short-term accommodation. Not only does this increase the level of mental distress for those involved but transient situations also complicate the follow-up for these children as they are transferred from one CAMHS service to another.

According to the mental health division operational plan 2017, there are 74 multidisciplinary teams. A Vision for Change recommended two teams per 100,000, which would equate to approximately 94 teams. This is a shortfall of at least 20. In the greater Dublin area alone, only 50% of the recommended multidisciplinary teams are operational. Again, these are not full teams. There are four day hospitals nationally. A Vision for Change recommended one for every 300,000. This equates to 15 day hospitals, meaning we have a shortfall of 11. There should be 100 beds nationally but there are only 48 operating currently due to staff shortages, particularly that relating to nurses. There are 20 beds in Cork but the unit only has the capacity for a maximum admission of 11 children. As the speaker before me mentioned, this is down to shortages of consultant and nursing staff. St. Joseph's unit in Fairview has 12 beds, of which only six are operational due to both nursing and medical staff shortages. The promised Limerick unit never materialised. The 20-bed unit in Galway appears to be fully operational. In the past month, the new purpose-built 22-bed unit in Linn Dara, which only opened 18 months ago, has closed 11, or 50%, of its beds due to nursing shortages. The unit has only 50% of the nursing resources required and the 11 beds were closed despite the fact that 20 children were awaiting admission. The consultant psychiatrist in the Wexford service is on leave and there is, therefore, no consultant cover in that area.

We know all too well that the net result of these bed closures and the under-provision in child and adolescent services is to further increase the unacceptable admission of children to adult mental health units. We witnessed a stark example of this just last month with the admission of a 16 year old to the adult mental health unit in Waterford. Adding to the trauma already experienced, this child had to spend the night sitting on a chair. As recently as last night, a 17 year old was admitted to a chair in Kilkenny adult mental health unit. Just over a week ago, another 17 year old in Kilkenny was admitted and remains on the unit. Both Waterford and Kilkenny are operating above capacity with the result that children are being admitted to chairs. To say 11 years after the publication of A Vision for Change that this is unacceptable is an understatement. CAMHS are in crisis and, as outlined, the provision of services is deteriorating rather than improving. There were 74 operational beds two years ago but 26 fewer beds are operational now.

Children and parents are being let down by the non-implementation of the policy and the lack of commitment or urgency in addressing the crisis yet we have known for 11 years what needs to be done to address the crisis. As a matter of urgency, the 100 beds recommended must be provided and staffed in order to provide quality therapeutic care and prevent further admissions of children to adult units. The number of community mental health teams must be increased as recommended and they need to be fully staffed and expanded to provide out-of-hours, home-based services. The criteria for clinical nurse specialists is too stringent and must be adapted in the short-term to facilitate an increase in applicants. There are approximately 20 unfilled clinical nurse specialist posts nationally, mostly due to insufficient applicants as the criteria is too strict. The recommended 15 day hospitals must be provided. The full implementation of these measures will only take place through a substantial increase in the budget for mental health services, which currently stands at 6.4% of the health budget.

Bizarrely and probably only in Ireland, we have witnessed a situation where, despite the growth in the demand for mental health services across the board, there has been a steady reduction in the mental health budget as a percentage of the overall health budget. According to A Vision for Change, the budget was 13% of the health budget in 1984, 10% of the health budget in 1994 and 7.1% of the health budget in 2004. The commitment to mental health services has diminished in each decade but the demand has never been greater. It is little wonder that the previous Taoiseach, Deputy Enda Kenny, admitted in the Dáil on 23 May last that mental health services have been neglected for over 30 years and were, as he put it, the Cinderella of many HSE Votes and Department of Health Votes. Looking at the mental health budget, it is sadly hard to avoid concluding that A Vision for Change was used as a cost saving measure on the backs of those with mental health issues.

Too often, we have seen the closure of beds with a paltry investment in community services. We struggle to provide vital services while trying to manage a severe shortage of psychiatric nurses, largely because our highly-skilled and committed nurses are being forced to leave the Irish health system for better pay, terms and conditions in the private sector, the UK, Australia and Canada, to name but a few of the market contenders. Who can blame them when there is a consistent failure to address pay and conditions in a realistic manner? That is the only realistic solution to stop the haemorrhage of our nurses to other countries and encourage those who are abroad to return. Something similar can be said about the medical profession also.

I thank the committee for the opportunity to outline briefly the extent of the ongoing crisis in child and adolescent mental health services which we know is impacting severely on parents and children. I assure the committee that the PNA is determined to see the issues in child and

adolescent services addressed before they deteriorate even further. We would welcome the committee's support in achieving the provision of a properly-resourced and staffed CAMHS which meets the needs of children, families and communities nationally.

Chairman: I thank Mr. Hughes and welcome Dr. Geoffrey Shannon.

Dr. Geoffrey Shannon: I thank the committee for its very kind invitation and I acknowledge publicly the outstanding work of Senator Freeman. It is important that an issue like mental health has a champion. I am here to express my personal support for the work she is doing, not only in convening this session but also in respect of the Mental Health (Amendment) Bill, which is very worthwhile. I had the opportunity overnight to examine it forensically and I have a few suggestions which I might share with the Senator privately rather than to detain the committee. It will make a very real difference.

I have often said that the measure of any democracy is the manner in which the needs of the most vulnerable are considered and met. There is no more vulnerable group than children with mental health needs. I have consistently raised, as Mr. Hughes referred to it, the Cinderella response to mental health issues. I have just finished what has been acknowledged as the largest worldwide audit of the exercise by a police force of its emergency child protection powers. I have looked at over 500,000 fields of PULSE data. One of the key messages emanating from my review of thousands of cases is that, linked to the substance and alcohol abuse one finds in many of them, mental health issues underpin much of the abuse. Across many of those cases there is substance and alcohol abuse. Linked with that there are mental health issues underpinning much abuse. What we have, as we heard from many witnesses this afternoon, is a lack of cohesion between services. The key finding from my report is that agencies operating under the umbrella of protecting vulnerable citizens need to work together seamlessly to protect children. We have poor inter-agency communication and co-operation across all agencies. My report shines a light on this. It is a unique window onto what happens when parents fail children and also when the State fails children. The State fails children when its agencies fail to co-operate to provide a service. My colleagues from the ISPCC referred to the need for a 24-hour service for families. Families operate 24 hours a day, seven days a week. They do not operate from 9 a.m. to 5 p.m. Our services appear to focus on 9 a.m. to 5 p.m. provision, and that must change.

I also acknowledge the outstanding work undertaken by front-line workers such as nurses, hospital doctors and consultants. Those professionals do their best at the coalface but we must ensure they have the proper infrastructure. The system fails many children experiencing mental health difficulties. The failure to recognise mental health issues at an early stage can have a profound impact on the family. After thousands of hours of work I found that warning signs are sometimes ignored, referrals are not timely and appropriate and the consequences can be devastating and cost the State much more in the long term. I listened to Peter Hughes and it struck me that we have had much vision but very little change. We need implementation. Senator Freeman will have heard me repeat on a number of occasions yesterday that we can have the best implementation plans in the world but unless they deliver for service providers, they are meaningless. We have had hollow promises which have not delivered for vulnerable citizens.

I also share the views expressed by the Children's Rights Alliance. I am delighted to be the founding patron of the alliance. The report card is a useful exercise in benchmarking where we are performing on key child protection issues. When a child is taken into the care of the State and is placed in a service, the State is saying it can do a better job. When the State fails those children it is failing them a second time. That can have devastating consequences. We are saying the care they receive in a family setting is not good enough but we fail to provide a better

service. We have raised expectations only for those expectations to be dashed in the context of poor communication between agencies and the failure to deliver on services.

The representative of the ISPCC referred to preventative services. I passionately share that view. Working upstream prevents problems downstream. If we seek to tackle these issues at a much earlier stage, it will relieve the pressures on mental health services at a later stage. Over a long number of years, and having reviewed thousands of cases, I have found that we are very good at crisis intervention but preventative services rank very much second best towards when we must deal with the crisis. We pump all of the finance into the crisis because it becomes a political issue. However, dealing with the matter in the first instance would have a much better outcome for both families and children.

I also believe that the system is unable to cope with children with emotional or behavioural problems or mental health problems. Again, the Children's Rights Alliance and the ISPCC referred to the fact that we end up exporting our problems to other jurisdictions, at a significant cost to the State. We must now develop home grown solutions to problems for our children. That must be done as a matter of urgency. Article 19 of the Convention on the Rights of the Child requires the State to protect children from harm and ill-treatment. It is a mandatory obligation to promote the welfare of children who are not receiving adequate care and attention.

In terms of international best practice in this area, I believe we must take a rights-based approach. We must consider the Convention on the Rights of the Child and its attention to four general principles. The first is non-discrimination under Article 2 of the convention. We are not treating children equally. We have heard a powerful story from another organisation, Be-Long To, that does outstanding work for children in minority groups who do not get the type of service they need.

The next principle is in Article 3 of the convention, the best interests of the child. I support the suggestion put forward by the Children's Rights Alliance in terms of defining "best interests" in the context of the Mental Health (Amendment) Bill. We must be able to benchmark what "best interests" means. We should set down a number of principles that would assist the court in determining, if there is a failure on the part of the State, what best interests means for children with mental health issues. I will be happy to share with Senator Freeman some suggestions as to how that might be realised. In 2012, the people of Ireland voted that children would have a special status in our Constitution. That must mean something. The people of Ireland said that the best interests of the child should be at the core of our decision-making. For that reason, I believe this is very good draft legislation. It attempts to prohibit the placement of children in adult psychiatric facilities, save in exceptional circumstances where it is in the best interests of the child. There is pragmatism in the proposal. It will put pressure on the State to ensure that more is done in this area. I believe this legislation will deliver and I urge Senators to engage with it in an enthusiastic manner. The legislation ups the ante in ensuring that we outlaw this practice. There are parallels. Ten years ago, everybody said we could not outlaw the detention of children in St. Patrick's Institution but it has been outlawed. It is not beyond the State to erase poor practices and practices that grievously breach its human rights standards.

The other standard is the right of every child to life, survival and development. Every child should have a fair chance in life, including those children who end up in psychiatric units because we do not have the correct facilities. I am no expert in mental health but why can we not have adolescent and child psychiatric facilities alongside each other? I am conscious of the difficulties that this Bill might create. I had an opportunity overnight to discuss it with a number of medical practitioners. Some concerns were articulated around the fact that there could be

a possibility of a child ending up in a hospital where the expertise is not available. However, we must come up with solutions, and this Bill is hugely important in providing the impetus for dealing with this issue.

Most important is the voice of the child. We heard powerful evidence this afternoon from BeLonG To on what it means for children. Those statistics are shocking, as is the fact that children in an LGBT setting could be so vulnerable. The State must react to this. I have always argued that the poor practices of the present become the tribunals of the future. For that reason, it is incumbent on the State to act in a speedy fashion. There was also a reference this afternoon to the UN Convention on the Rights of Persons with Disabilities. There is no need to wait for the ratification of the convention. The Children's Rights Alliance referred to Article 24 of the Convention on the Rights of the Child, which states that every child has the right to the highest attainable standard of health. By any standard, placing a child in an adult psychiatric facility does not equate with the highest attainable standard of health. Very useful guidance is provided on Article 24 in general comment No. 15. If members are in any doubt as to what that provision means, they should look at general comment No. 15. I would argue that the State, by allowing children to be placed in adult psychiatric facilities at present, is grievously breaching international law. If we are concerned about our reputation internationally, we will move very quickly to address this huge injustice for children. Another provision that is arguably breached is Article 3 of the European Convention on Human Rights, which prohibits inhumane or degrading treatment. I defy anybody to say that placing a child in an adult psychiatric unit is not inhumane or degrading treatment. The European Convention on Human Rights, which is binding on all State bodies, albeit it has been introduced at a sub-constitutional level, provides, under Article 8, that the best place for a child is within his or her family. If we are taking the child out of the family into what I would describe as a sub-optimum environment, in other words an adult psychiatric unit, I argue that we are in breach of Article 8 and also Article 3 of the European Convention on Human Rights. It is also arguably in breach of the Constitution under the new Article 42A. There are two such provisions of the Constitution, namely, the new children's right provision and the personal rights provision in Article 40.

I am conscious of the time constraints. Pages 72 to 75 of my report document poignantly mental health issues arising for those children who require an emergency out-of-hours service. It is quite striking that many of those children access the Irish Society for the Prevention of Cruelty to Children, ISPC, line. I wish to publicly acknowledge how important the ISPC's Childline is for children. In the sample that I ended up examining, I was surprised to that so many of the children had accessed the Childline service. The service does an outstanding job protecting very vulnerable children.

Children aged between 16 and 18 are in what I would characterise as the twilight zone. Those are the children who most suffer because they are neither getting a child service nor an adult service. We need to make sure that their rights are fully vindicated.

I would argue that childhood is for a limited period of time. If we do not provide the right service at the right time to a child, it will have very significant consequences. I remind those in this Chamber that childhood, once it is interrupted, cannot be restored.

Chairman: We have about an hour for questions. As Dr. Shannon will be leaving early, I ask members to address their first questions to Dr. Shannon.

Senator Joan Freeman: Before I ask my questions, I wish to point out that a common theme in this session has been the passion expressed by the witnesses. All of them have a

passion to help the child and the most vulnerable. That was obvious from each of them. The session this morning was very harrowing but having listened to our guests, I have hope. Dr. Shannon has come out with the most profound statements. Yesterday, he stated his hope that after the outrage there will be action. I hope there will be action now. He also noted that the State takes over responsibility for our children, thinking it can do a better job, and we have not seen that yet.

I have two questions and I will group them.

Chairman: Yes, group them together.

Senator Joan Freeman: I will address a question to Mr. Peter Hughes, who mentioned that one solution to increasing staff levels or recruitment and retention of staff is to do with pay. He was involved in the pay talks recently. Where is the problem here? We are told constantly all the time by the HSE that we cannot recruit staff, so where is the problem?

Ms Mary Nicholson from the ISPCC was right in that we need young people to be in here talking. We tried to get them to come. I was conscious of the fact that they were terrified that they would be stigmatised for life. That is why they did not want to speak but we are here to speak on their behalf. That is why it is very important today that we do so.

Dr. Maria Migone is very much on the front line and every day, she sees a relentless number of terrible challenges. On a personal level, what is that like for her?

Senator Colette Kelleher: I have a few questions. In our deliberations we will take on board the views of the groups that have highlighted particular risks. Compared with the wider population, people who are LGBT suffer two times the level of self-harm, three times the level of attempted suicide and four times the level of severe or extremely severe stress, anxiety and depression. Young people with intellectual disabilities experience a higher incidence of mental health difficulties and yet they are the ones who cannot access the system because they do not fit in either. It is extraordinary. Mr. Peter Hughes rightly reminded us that approximately 2,500 children will be living in emergency accommodation tonight. What will their mental health be like tonight, what will it be in the future and will we have the tribunals that Dr. Shannon talked about?

The voice of the child is critical. It was great to have Ms Arianna Gallagher in here earlier. The idea of an independent advocacy service is one that I fully support. It was brought up by both the ISPCC and the Children's Rights Alliance. We are getting the same messages this afternoon as we got from the mothers during the earlier session this morning. Our children are falling through the cracks, of that there is no doubt, between Tusla, the child and adolescent mental health services, CAMHS, and in terms of disability where one can be either too young or too old if one is 17 or 18 years of age and, as we heard from Ms. Julie Helen's case studies, one's diagnosis can be either too mild or too severe or one can have autism or a dual diagnosis. I would be interested to hear from Dr. Shannon what a good system looks like, where has he seen it in place and to where can we look for it?

I would ask Dr. Maria Migone if every child and adolescent mental health service is led by a psychiatrist and is that necessary? Is that getting in the way of us getting to grips with the fact that we do not have enough teams in place?

If there was only one item our guests would like us to put in the report, what would that item be?

Chairman: I call Senator Pádraig Ó Céidigh.

Senator Pádraig Ó Céidigh: Does Senator Devine wish to speak first?

Chairman: Which of the Senators wishes to go first?

Senator Máire Devine: I will speak first.

Chairman: A brief question, please.

Senator Máire Devine: It has been an interesting day. We deal with these matters in terms of questions concerning mental health facilities at the Joint Committee on Children and Youth Affairs, which is ongoing. In the context of mental health reform, the priority is approved centres. Therefore, we have a dearth of child and adolescent mental health services because we have to go with the approved centres in the first instance because that is stipulated in legislation. It was mentioned that legislation should be enacted to ensure that CAMHS funding is ring-fenced in its own right and cannot be touched or go back into the adult services. I would like our guests to expand on that.

Reform of the Mental Health Act, which Senator Freeman is trying to progress, should provide for a stand-alone child section. That is worthy of inclusion and perhaps we are beginning the consideration of that here.

I thank Mr. Peter Hughes, my colleague from the Psychiatric Nurses Association. He mentioned that almost 3,000 children in Dublin alone tonight will be without a bed. They could represent the Magdalen laundries of the past and the tribunals of the future. We need to cognisant of that and to act well.

We need to realise that we do not have a single mother and baby bed for postpartum women, which is significant. We have nothing in place to embrace a mother and baby at the start of the baby's life. The public health nurse has a important role to play for mothers who need help at home. In addition to only ticking the boxes for eye co-ordination, hearing, balance and so on, there also needs to be a box for mental well-being and emotional well-being. We need to train our public health nurses in that. I know there are psychiatric and intellectual disability nurses in our union but it would be interesting to approach them to see if we can change that in the school of nursing.

In respect of the Lucena Clinic I am a strong advocate of, and believer in, group therapy where it is possible and necessary. I know the service gets individual referrals but has Mr. Hughes thought perhaps of the milder form of distress among teenage girls and boys and that there is perhaps an opportunity for some sort of regular group therapy at school, with a professional, to explore what is happening in the mind of a teenager? We all went through it but growing up can be distressing. It might be helpful to steady the group, give them a sense of themselves and a sense of empowerment so that no matter what they do, the outcomes will be good. It will help them reach adulthood, to mature and maintain loving relationships and contentment with life. Given that there is such a big demand on psychiatric nurses could the schools provide some sort of group therapy that is more cost-effective but also more emotionally effective?

Senator Pádraig Ó Céidigh took the Chair.

Acting Chairman (Senator Pádraig Ó Céidigh): I will ask Dr. Shannon to answer all our questions first because he has to leave at 4 p.m. I have two questions: what are the short-

term quick wins we can put into the report that would be cost-effective? I am referring to some valuable points Mr. Jackson made. There are many organisations all doing their own thing, working in silos. Is there something we can recommend that will start moving the ball in the right direction?

What is urgent and important that needs to be done now, and what is not as urgent but still important? That is down to strategy, what needs to be done when?

Dr. Geoffrey Shannon: I am happy to answer any further discrete questions. In response to the question about inter-agency cooperation and what models I have examined, to provide insight, I am passionately of the view that co-location is a real solution. I have visited several centres and reviewed several models of inter-agency cooperation. I emphasise throughout the audit report that notification is not communication. There is a tendency among State agencies to feel that if they fill in a form and push it on the problem is solved. There is also a lack of respect for the discrete professions. One sometimes thinks it has greater insight than another. A stand out example was a centre I visited in the Bronx, established to review child abuse where there was someone from the New York Police Department, NYPD, social services and a forensic paediatrician. All of the professionals were working together trying to map a solution for the individual child. What happens too often is that the focus is not on the child, it is on generic services. The ISPCC made the point that the solution is all too often a package. We need to build solutions around children rather than around available services. There needs to be a fundamental review of how agencies cooperate with each other. That is the international trend. There is also an interesting approach in Manchester and London, the multi-agency model where agencies work together on site to find solutions. We need fundamental reform. We have seen A Vision for Change and little change. We need to consider what will open those road blocks. I am happy to feed in to this report the extensive research and insight that I have obtained internationally in two years of conducting the audit report.

Acting Chairman (Senator Pádraig Ó Céidigh): That would be very helpful. Dr. Shannon's contribution would be greatly valued and appreciated.

Mr. Peter Hughes: In answer to the questions specifically to me, yes we have come out of pay talks and the pay commission in its report highlighted the recruitment and retention issues for psychiatric nurses as a key area of difficulty. Although we made an effort to say it was urgent and needs to be addressed and we hoped to engage further on it, there has been no urgency in addressing the issue.

The 11 beds in the Linn Dara services closed because they did not have enough nurses. They had only 50% of what they should have had. Most of the staff in Linn Dara are relatively newly qualified and they are going abroad. Even within Ireland private services give them incentives and will pay a certain amount up front if the nurse will stay two years. They go to the UK and Australia, where their education is supported, they get time off to do it, it is paid for and they have subsidised accommodation. The NRS is building 20,000 units for staff accommodation because it knows this is a problem. The high rents in Dublin were mentioned. That needs to be addressed, whether through subsidised accommodation or a rent allowance. Nobody is listening but we are losing the nurses year on year. A graduate scheme was brought in to pay 85% of the staff nurse salary for the first two years to those people who qualified and then 90%. The majority of them emigrated and it would be very difficult to get them back. That was one of the biggest insults to any profession, not to pay the salary after people had done a four year honours degree. Those people have left with a seriously bad taste in their mouths. We need to keep the people we have here and to keep those who will be trained in the next few years.

Senator Devine mentioned that there is no mother and baby bed in the country. When I started training as a psychiatric nurse and for several years after that, there were several mother and baby beds. Twenty-five years on, we seem to be stepping backwards instead of forwards. Two years ago there were 74 operational beds. We are now down to 48. One always imagines that services will gradually improve rather than deteriorate. We are seeing the deterioration of the child and adolescent services rather than their improvement.

Senator Paul Coghlan resumed the Chair.

Senator Pádraig Ó Céidigh: Various Governments and Ministers for Health have made efforts to bring the nurses back from abroad. What is Mr. Hughes's experience of returning nurses?

Mr. Peter Hughes: There was a "bring them home" campaign which probably cost hundreds of thousands of euro. Two recruitment agents went to the UK. Nine psychiatric nurses applied, six came back and I think there are four left. That was a year and a half or two years ago. That is the impact that had. Much of that relates to the group I am talking about who left with a sour taste in their mouths, for want of a better description. However, there was not enough incentive to return. They were being offered €1,500 that had to be vouched. When they looked at the salary, the price of rent, educational opportunities and so on, I would say the majority said they were better off where they were.

Senator Joan Freeman: Dr. Migone and Dr. Kavanagh were asked a question while the Chairman was out.

Chairman: We have heard from Mr. Hughes and Dr. Shannon, so if the others would like to come in now, please do.

Dr. Glenda Kavanagh: I will try to remember all the questions asked. We have heard many difficulties about the CAMHS. There is probably too much emphasis on what CAMHS can do and what we are funded to do. As Dr. Migone pointed out earlier, we see the most unwell 2% of the population. There is a lack of infrastructure below that. We heard about the preventative piece and more and more is being pushed into CAMHS either because people are waiting or because of a lack of other services - for instance, autism services in this country are very poor. These are group of young people who are very vulnerable to mental health difficulties. We often end up seeing them in very crisis-bound states and they are very difficult to treat because of their difficulties. Without the care underneath that there are more coming through to us. There are many young people using our services who have autism and that is similarly the case with intellectual disability. I strongly advocate for intellectual disability teams that are very specific. That requires very specific training and those in CAMHS are often not trained enough to be able to take on that cohort.

Senator Colette Kelleher: There was the question of whether it always has to be psychiatrist led. I am interested to know in that some teams cannot operate because they do not have a psychiatrist. Obviously, one needs to have access to a psychiatrist but whether they need to be led by a psychiatrist is the question.

Dr. Glenda Kavanagh: Traditionally, that is how our services have been. Dr. Migone referred to the young people who are accessing them. They are young people with mental health disorders such as psychosis, anorexia nervosa, major mood disorders and all those types of things that absolutely need psychiatry to be part of the team.

Senator Colette Kelleher: The question related to psychiatrist led.

Dr. Glenda Kavanagh: One could argue that point. I feel that is the training we have had to take responsibility for these young people. One might ask other disciplines if they would prefer it to be led another way and that is a discussion that could be had. I think it works well because that is the training we have had. It is not merely the medical piece but also the management of the team which represents a good percentage of our time. That is what our training has led us to do. I think the answer is “yes” but the Senator might find other people who will say “no”.

Senator Colette Kelleher: Managers come from a variety of backgrounds and disciplines. The idea of having access to a psychiatrist is critical. I would also like to ask another question about leadership.

Chairman: Does Dr. Migone wish to add to that? I saw her nodding her head.

Dr. Maria Migone: There was a question about what it was like having to provide that service. It is stressful, and one feels guilty much of the time because one is not offering the service that one would like to offer. That is the truth. I think that is why many people have left, because they found that very difficult to deal with on a personal basis. We are not blaming anyone for this. The HSE staff that we deal with are aware of the difficulties but there is only so much they can do if they do not have the funding. They cannot do anything either. It is stressful for people and that is why they leave.

Chairman: Does anyone else have a question to answer?

Dr. Shari McDaid: On Senator Kelleher’s question about what one thing we would put into the report, it is a challenge to select only one. The Children’s Mental Health Coalition has produced a report on child and adolescent mental health supports spanning from primary care to tertiary would look like. We can provide that to the committee. If we had to chose one thing that would make a big difference it would be building up the primary care mental health services. Many of the difficulties that arise for child and adolescent mental health services are because we had utterly neglected the primary care mental health services. One of the problems with A Vision for Change is that it never specified what primary care mental health should look like, nor did the 2001 primary care strategy. In that vacuum, it has been completely overlooked - over what is almost 20 years since the primary care strategy was published. We think that would be helpful.

On things that might offer quick wins, improvements to the co-ordination of services to children and adolescents and young people who also have an addiction problem would be helpful. We often hear a view in mental health services that someone needs to deal with his or her addiction before they can access mental health treatment. That is not realistic in children’s behaviours. It would be helpful if we could adopt an approach of no wrong door, where mental health and addiction services could work together and no child would be turned away or told that it was not appropriate for him or her to get help just because he or she has an addiction.

Senator Devine asked about the ring-fencing of funding. That might have come from the ISPCC; I do not think it was from us. Ironically, at the moment funding is not the biggest problem. There are funds but it has not been possible to spend them. The HSE’s mental health division’s operational plan shows that at the end of December, there was the equivalent of almost 1,500 vacant posts between development posts that had not been filled and posts that were being covered by agency staff and overtime. It would be a first step if we could fill the posts

to which there is already a commitment. Of course, we would advocate that in the context of next year's budget the development funding required to keep the reforms on track should be allocated.

Senator Devine also asked about the Mental Health Act. We have advocated that there should be a separate section in the Act for children, to reflect the best interests of the child. There should be specific principles in a section of the Mental Health Act that are appropriate to children which would be distinct from the principles that are appropriate for those who fall under the Mental Health Act who are adults. We have clearly said that 16 and 17 year olds not being able to consent to treatment is not in keeping with their human rights and should be rectified urgently. Something needs to be done about the process for involuntary admission of children, where decisions are made that children have to be admitted to hospital, to make sure the voice of that child is heard in proceedings. We are not sure that the court process is facilitating that at the moment. That is our response.

Chairman: I thank Dr. McDaid. Is there any question that Mr. John Duffy wants to answer?

Mr. John Duffy: One thing Senator Kelleher asked about was what we would like to have in the report. From my perspective and perhaps from that of BeLonG To as well, positive coping strategies should be instilled among young people from a very early age. This does not really happen across the board for young people and it could really benefit young people, for example in education - I think that is a natural place where some of that work can happen. That is really important from our perspective because of what we have been seeing within our service. Pieta House came in and is providing a service with us at the moment. When it first opened up, we thought that the service would be oversubscribed from a very early point, but unfortunately, young people from the LGBTI community have such a low expectation for their mental health that they thought that it is normal to self-harm and okay to think about suicide. It was not until our youth workers and other staff members started talking to young people and saying that that was why the service was there for them that people started coming into the service much more frequently, to the point now that the staff member from Pieta House in our service is kept very busy.

The issues of minorities relate to that. It is not just LGBT young people that need to discover more positive coping strategies, such as help-seeking or solution-focused strategies around mental health. It is also related to - as Inclusion Ireland has said - those with disabilities, young Travellers, asylum seekers and refugees. There is a much larger range of individuals than just those I have mentioned. There really needs to be a focus on those minorities that are more likely to experience higher levels of morbidity around mental health, because of the stark statistics that are there, as have been indicated by myself and others here today as well. There should be a focus there.

Ms Sarah Lennon: I will follow on from much of what Mr. Duffy has said. Inclusion Ireland has stressed and Senator Colette Kelleher has reflected back to us the importance of highlighting people with intellectual disability in this regard. I mentioned a figure of 25%. That is a HSE figure. We know that at least one in two people with an intellectual disability has no contact with health services at all. They are in the community. They include members of the Traveller community. We know that Travellers are five times more likely to have either an intellectual or a learning disability. We know that 40% of young people under the age of 16 on custodial remand have a learning disability. We know that about 40% of people who were homeless have a disability. These people are not necessarily in contact with health services. They are in the community. We need to think a little bit - and I do not know whether it is beyond

the bounds of the report - about why. We have people who are resource deficient and socially isolated who have intellectual disability and are experiencing mental health difficulties. There are other things that we can do that are beyond the treatment we can give. Early intervention is absolutely an option, but what can we put in place structurally to prevent people from becoming socially isolated? There is much research, including the likes of the longitudinal study on aging. The intellectual disability supplement to that said that people with intellectual disability are twice as likely to be socially isolated as anybody else is. That level of isolation and resource deficiency has a huge role to play in people's mental health.

Chairman: Do Ms Julie Ahern or Ms Saoirse Brady from the Children's Rights Alliance wish to answer a question?

Ms Saoirse Brady: It is very hard to say what one thing would make a difference. I take it that I can say something different from my colleagues and that it will be added to the report as well. What is very clear from having BeLonG To, Inclusion Ireland, the ISPCC and our other colleagues here is that having an advocate - somebody who can speak on behalf of a child - is essential for this. Maybe the child does not need to go to CAMHS, but rather to a different service. It is important that a child can be directed to the help he or she needs at an early stage.

At the end of last year, the Children's Rights Alliance produced a "Know Your Rights" booklet with the Irish Council for Civil Liberties and we ran a training session with more than 100 different service providers on mental health itself. Those providers came from statutory bodies such as Tusla and from many of the homeless services because there is a huge issue there and they do not know how to cope with young children and adolescents, their mental health and family mental health as well. There were also front-line staff from St. Patrick's Mental Health Services, which helped to fund that training programme. We travelled to Galway, Cork and Dublin. There is an appetite for training. Something that Inclusion Ireland said about accessible information about what one's rights are is essential in this area. I would build on that as well.

Something else that was said, that both the ISPCC and Dr. Geoffrey Shannon alluded to, on having mental health services here in Ireland, is going to become even more real with Brexit. We need to ensure that we have the services here and that we do not need to export children, because there will be issues there, and that is something a number of us are looking at as well.

Ms Mary Nicholson: With regard to the voice of the child, I do not necessarily think that this is the environment, but a mechanism to ensure that children are represented should be found. On what we would really like to see, I will add to what Ms Saoirse Brady said. If there were 24-hour services, it would prevent many things from escalating. It would sometimes prevent the need for other things, along with early intervention. Sometimes, there is a view that 24-hour services cost much money. It is not about that for us. If one looks at the North, it has an out-of-hours 24-hour social work service, and part of that social work service has a huge amount of mental health professionals within it. The social workers are trained in mental health, and that costs £3.6 million a year to run. That is not a huge amount of money to provide 24-hour support for child protection and mental health, whatever the needs of the child and people in the community are.

Dr. Geoffrey Shannon: A key question on systemic reform needs to be addressed. The current legislative framework is deficient, in my opinion. When the Mental Health Act was drafted, there was far too little focus on the discrete rights of children. It comes into sharp focus in these cases when they arrive before the District Court. We are relying on a separate piece of

legislation. We now need a cohesive legislative framework. We need broad structural reform. That structural reform needs to reflect the commitments given in the Constitution that children have discrete rights. At the top of my wishlist would be the Mental Health Act having a separate section on children. There would not only be a separate section on children, but some level of cohesion between all of the different pieces of legislation, so when a child comes before the District Court, that child may very well have mental health issues, and we lack a bridge between these discrete areas. We seem to think there is just the mental health issue, that will be dealt with separately. What I found quite striking about the audit report is that many children were made subject to the Mental Health Act in the context of a child care issue arising. We need a broader vision as to how to deal with both the child care dimension and also mental health issues that parents may very well have.

Ms Julie Helen: One of the biggest things that will change things for young people is inter-agency working because so much else will flow from that. We heard this morning from others, very strongly, about how their children were falling through the cracks. They were falling between the stools at different stages along the way, and much of the time, unnecessary extra mental health difficulties followed on from that. We heard from Ms Lauren Keogh, who told us about her daughter, Zara, who unnecessarily experienced anorexia because she was waiting for mental health services. We heard from Lauren Keogh. She told us about her daughter, Zara, who experienced anorexia unnecessarily because she was waiting for mental health services. Similarly, many of the case studies I detailed in my opening remarks relate to self-harm and talking about suicide. However, those issues started far earlier in the life of that child or young person. If we had more inter-agency working and joined-up thinking, as we discussed this morning, our children and young people would be far better able to become self-advocates and peer advocates. Everyone would be working together and our children and young people would know that they are important, that the system is in place for them and that they can speak up for themselves and for each other. The ultimate goal in advocacy is to speak up for ourselves and for each other. It is true that we are all sitting here as advocates for other people, but the ultimate aim is that people can speak up for themselves. Many things will aid that and flow from that. Accessible information will help people to be self-advocates and to look after their mental health. That is what we should all be aiming for as citizens in Ireland.

Chairman: Are there any final words on the members' side?

Senator Joan Freeman: I thank all the witnesses. I have worked with many of them and their agencies over the years. It was a pleasure to hear them speaking today. In particular, I thank Peter Hughes, who is really telling the world what our nurses and doctors have to put up with. I hope that we can work closely again.

I said to Dr. Shannon yesterday that he makes me breathless because his reports are so detailed and compassionate. We need Dr. Shannon to show us the way. He is a mine of information.

Senator Colette Kelleher: I have been blown away. We have in mind minorities and the 1,200 children in direct provision. We have in mind children from Traveller backgrounds. While we did not have them before the committee today, we are mindful of them. I thank Mr. Duffy and Ms Lennon for reminding us of them.

Ms Helen noted that we all have responsibility for our mental health. Inter-agency co-operation seems to be the key measure to ensure that the child is at the forefront rather than whether a person is a social worker, psychiatrist, occupational therapist or none of the above. It is about

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the child. If we get that right, I think we can go a long way on the legislative reforms. I thank all our witnesses for being inspiring.

Senator Máire Devine: I am proud that this has happened in the Seanad. We are the Upper House, by the way, not the Lower House.

Chairman: That is why we are upstairs.

Senator Máire Devine: I am absolutely proud. Mr. Hughes referred to the clinical nurse specialist and advanced nurse practitioner roles and how we have to bring down the criteria. There are many easy solutions there.

I want to end with the two words that simplify the crisis: Linn Dara. I have raised it every day in the Seanad on countless occasions. I keep throwing the name out and keep accosting Ministers when I see them in the corridors, appealing to them to bring back the 11 beds. It is easily done. We should simply do it because that really tells us about our commitment to child mental health services.

It was great to meet all the witnesses and I am sure we will all work well together in future. Many thanks to gorgeous Joan, Senator Freeman, as well.

Chairman: On behalf of the Seanad Public Consultation Committee I thank all of you as well as those who contributed this morning. I believe it has been informative and productive. We have all learned a great deal from your insights and observations. Full account will be taken of today's discussions when a draft report is being prepared. Copies of the final report will be sent to all of you.

The select committee adjourned at 4.15 p.m. until 10 a.m. on Thursday, 6 July 2017.