

DÁIL ÉIREANN

AN COMHCHOISTE UM SHLÁINTE AGUS LEANAÍ

JOINT COMMITTEE ON HEALTH AND CHILDREN

Déardaoin, 12 Samhain 2015

Thursday, 12 November 2015

The Joint Committee met at 9.30 a.m.

MEMBERS PRESENT:

Deputy Catherine Byrne,	Senator Colm Burke,
Deputy Joe Costello,	Senator Thomas Byrne,
Deputy Seamus Healy,	Senator Imelda Henry,
Deputy Colm Keaveney,+	Senator Jillian van Turnhout.
Deputy Billy Kelleher,	
Deputy Sandra McLellan,	
Deputy Mary Mitchell O'Connor,	
Deputy Dan Neville,	
Deputy Caoimhghín Ó Caoláin,	

+ In the absence of Deputy Billy Kelleher for part of the meeting.

DEPUTY JERRY BUTTIMER IN THE CHAIR.

Child and Infant Mental Health: Discussion

Chairman: In our first session this morning we will discuss child and infant mental health services. I welcome Professor Kevin Nugent, director of developmental medicine at Boston Children's Hospital and faculty member at the Harvard Medical School; Dr. Paul D'Alton, president, Psychological Society of Ireland, who has attended committee meetings and is a good friend to the committee; Ms Kate Mitchell, co-ordinator, and Ms Lara Kelly, communications and campaigns officer, Children's Mental Health Coalition. Ms Kelly has also been a very good advocate and friend of the committee. I thank all of our guests for being here. It is a great pleasure to have Professor Nugent at the meeting as he is a leading Irish academic teaching in Harvard, but he is also an international expert on infant mental health. He is most welcome back to Dublin. I welcome our other guests who have been involved in different aspects of the work of the committee in the past couple of years.

By virtue of section 17(2)(I) of the Defamation Act 2009, witnesses are protected by absolute privilege in respect of their evidence to the committee. However, if they are directed by it to cease giving evidence on a particular matter and continue to do so, they are entitled thereafter only to qualified privilege in respect of their evidence. They are directed that only evidence connected with the subject matter of these proceedings is to be given and asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person or an entity by name or in such a way as to make him, her or it identifiable.

Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside the Houses or an official, either by name or in such a way as to make him or her identifiable.

I invite Professor Nugent to make his opening remarks.

Professor Kevin Nugent: Tá an-áthas orm bheith os bhúr gcomhair anseo inniú; is mór an onóir é. Déanfaidh mé mo dhícheall bhúr gceisteanna a fhreagairt agus pé saineolaíocht atá agam a thabhairt daoibh. Go raibh míle maith agaibh.

I feel especially privileged to be here to discuss some of the research in which my colleagues and I have been engaged for the past 35 years or so at Boston Children's Hospital and Harvard Medical School and that of colleagues both here and abroad. I am particularly grateful as a researcher to be talking to policy makers because there is often a wide gap between research and public policy. It is very gratifying for me to be able to share these ideas with the committee.

My focus is on the youngest members of society, those who literally do not have a voice - infants and toddlers. Committee members perhaps assume they have very little to say because they cannot say much, as I once assumed. We understood very little about their minds, hearts and brains. The foundations of sound mental health are built in the first three years or 1,000 days of life. These early years provide the essential foundations of stability for all other aspects of human development, the capacity to face adversity, to have friendships, to have success and happiness in school, the community and work. They are crucial for the long-term health of any society.

I wish to cover five key points: brain development in the first three years, or 1,000 days, of life; the influence of early experiences on brain development; the importance of prevention rather than treatment for children in adverse environments; the need for professional training in

infant mental health; and indications for public policy.

For much of the 20th century, many people, including many scientists, severely underestimated the mental and social capacities of infants. We assumed, for example, that newborns could not see, that infants could not think or that, if they could, their thought processes were concrete, immediate and extremely limited. We also assumed that infants were fragile and had a narrow emotional range. We failed to be convinced that babies could grieve, be sad or even traumatised. We - nurses, doctors, psychologists, therapists and teachers - tended or perhaps wanted to believe young children did not quite understand what was happening around them, or were so resilient that they would simply grow out of the problems they were facing. That infants and toddlers could have mental health problems was beyond our ken. The field of infant mental health had not yet emerged. However, all that has changed. In the past 30 years there has been a revolution in our understanding of the capacities and inner lives of babies and toddlers and, in particular, the workings of the infant brain. Brain development in the first three years of life is more extensive and vulnerable to environmental influences than in any other period in one's lifespan and has a longer term impact than was previously thought. We now know that the brain doubles in size in the first year of life. By age three, the brain is at 80% to 90% of its adult volume. Even more importantly, the synapses - the connections between neurons and brain cells - are formed at a faster rate during these years than at any other time in life. In the first years of life between 700 and 1,000 new neural connections are formed every second, as the brain builds synapses. If any member of the committee goes home tonight and meets someone under three years, he or she should look at that little girl or boy in the eye and realise this is happening. All of the synaptic connections in the child's brain are being stimulated and the adults around him or her are contributing to his or her well-being as he or she is building up his or her brain architecture.

The environment influences brain development; the process of building the brain is not genetically determined. Between birth and the age of three years, children's brains are malleable and more plastic than at any other time in their lifespan. Sensitive and responsive caregiving is a requirement for the healthy neurophysiological and psychological development of a child. It even mediates lifelong outcomes. We know that during the first three years children's long-term capacities to think, understand, trust, empathise and feel concern for others are being fundamentally shaped. By age three years, the child's orientation towards life is very firmly established. This means that the relationship between parents, caregivers and all who make up the child's network are critical in shaping that little brain. The people mentioned set up the child's expectations for life. On the other hand, strong, prolonged adverse experiences such as extreme deprivation, abuse, neglect, exposure to violence or the absence of supportive adult relationships can lead to changes in the physical structure and functioning of the brain. Such changes include chemical responses, impaired cell growth, changes in the proteins and other molecules produced by the brain, the death of neurons and interference with the formation of healthy neural networks. The strength and quality of the child's relationships are critical.

The importance of prevention rather than treatment must be emphasised in this regard. By preventing problems from developing in the first place, not just treating them after they have occurred, we can undo the effects of these early adverse experiences. The earliest years of life present the greatest opportunity for preventing and mitigating harm from trauma and setting the course for optimal development. In the case of child maltreatment, for example, there is a shift towards a prevention promotion framework rather than just addressing it when it actually occurs. Our aim is to strengthen the capacity of parents and communities to care for children in ways that promote optimal health and well-being. The research paradigms have shifted our fo-

cus towards strengths-based approaches to prevention and towards valuing what parents bring to the table in the first place rather than labelling them or taking a pathological approach. Our approaches should allow parents to dig deep and we should be looking at the social and cultural capital within communities on which parents can draw in bringing the best out of their young children.

The need for professional training in infant mental health is also significant. Physicians, nurses, psychologists, teachers, providers of early care and education, physiotherapists and occupational therapists, speech pathologists, social workers – anyone who has responsibility for the care of infants and toddlers – should be required to seek professional training in infant mental health to better understand and appreciate the inner world of infants and their parents. Anybody who comes in touch with a baby and its family and who has responsibility for the care of infants and toddlers should be required to receive this training as it enables them to have a sympathetic understanding of what is happening in the child's life, as well as a non-judgmental approach towards parents. Nothing can really replace an informed and sympathetic understanding of the needs of infants and families or a non-judgmental and culturally respectful approach to parents and their families.

In Ireland we have the Irish Association of Infant Mental Health which provides training for professionals from a range of disciplines to prepare them to promote early social and emotional development in babies and toddlers and the establishment of healthy and secure attachment relationships. Having a new cadre of professionals trained in infant mental health will undoubtedly reduce the burden of mental health problems for future generations and allow for the full development of vulnerable children.

On the implications for public policy, early disadvantage such as the impact of poverty, ill health and other adversities such as homelessness can have a significant influence on children's future progress. More often than not, such disadvantages are beyond the control of individual families. That is why I am grateful to be before the committee. Policies that support families and communities are critical, as the strength and quality of the relationship between caregivers, families and their children are fundamental to the effective development of children's brain functions and capacity. Besides, as James J. Heckman, who was awarded the Nobel Prize in Economics in 2000, pointed out, early interventions with infants and toddlers result in much higher economic returns than later interventions. Although early intervention is never too late, at age three years, just before school, it is very late. Initiating programmes that meet the developmental needs of children from birth to age three years is as much about building a strong foundation for lifelong physical and mental health as it is about enhancing readiness to succeed in school. This approach puts families and children at the centre of a multifaceted model that includes building protective practice for families, reducing risk factors for children, strengthening local communities and connecting all this through systems change and policy.

I thank the committee for giving me the opportunity to address it. I feel very privileged.

Chairman: I thank Professor Nugent for his very informative, interesting and challenging presentation. I now ask Ms Mitchell to make her opening remarks to the committee. She is the co-ordinator of the Children's Mental Health Coalition.

Ms Kate Mitchell: I thank the joint committee for inviting representatives of the Children's Mental Health Coalition to appear before it. We circulated copies of our report, Meeting the Mental Health Support Needs of Children and Adolescents: A Children's Mental Health Coalition View, to members in advance. I am co-ordinator of the coalition and policy and research

officer at Mental Health Reform which provides the secretariat for the coalition. I am accompanied by Ms Lara Kelly, our communications and campaigns officer. The coalition consists of more than 50 member organisations and concerned individuals from a range of backgrounds and sectors, including children's rights, human rights, education and mental health services. Its key objective is to advocate for improvements in child and adolescent mental health services and supports.

The coalition acknowledges that there have been positive developments in child and adolescent mental health services and supports in recent years. Such developments include the expansion of Jigsaw direct access supports; an increase of 153 clinical staff in child and adolescent mental health services, CAMHS, between 2008 and 2015, from 352 to 505; and a decrease in the number on waiting lists from 3,117 in 2008 to 2,240 in August 2015, despite increases in the level of service demand. The number of children and adolescents waiting more than 12 months to be seen by CAMHS has also decreased, from 897 in 2008 to 241 in August 2015. Additional developments include the publication of the standard operating procedures, both inpatient and community, for CAMHS, the roll-out of the *yourmentalhealth.ie* campaign, publication of the national guidelines on mental health promotion and well-being for both primary and post-primary schools and the establishment of the ACT service in Oberstown national children's detention facility.

Despite recent Government efforts, the reality is that significant challenges continue to exist for a wide range of families and children who require mental health supports across the country. These challenges concern prevention, access to supports, effective co-ordination between agencies and ensuring the voice of the child is heard. In terms of early intervention, it is now widely accepted that the foundation for healthy, psychological, social and emotional health across the life span is developed in infancy and early childhood. Gaps that exist in the area of infant mental health include the absence of clinical psychology and-or parent-child psychotherapists in maternity hospitals, a lack of training on infant mental health among staff working in maternity hospitals and the absence of child-specific public health nursing posts. These gaps in services should be addressed through allocated funding. Furthermore, while the publication of the national guidelines on mental health promotion and well-being is positive, there is a need for a clear implementation plan and effective resourcing to ensure the guidelines translate into action. Training and support for schools is needed in order to implement a whole-school approach.

Access to mental health services and supports is often difficult for children and families. The coalition attributes such difficulties to a number of factors, including inadequate capacity in primary care, restrictive referral criteria for access to community-based CAMHS, a lack of specialist services, the low number of child and adolescent inpatient beds, lengthy waiting periods, a lack of information about what to do during the waiting period as well as difficulties in navigating the child and adolescent mental health system. The HSE has reported that between January and August 2015, 29% of all child and adolescent admissions to acute units were to adult inpatient wards. This is only a marginal decrease, approximately 5%, on the proportion of child admissions to adult inpatient units when *A Vision for Change* was first published in 2006. It is well evidenced that adult inpatient units are not appropriate, safe environments for children and adolescents and that care in such settings may be ineffective.

The Ombudsman for Children recently reported that a number of complaints submitted to his office were about children being inappropriately placed in adult inpatient facilities, in particular children at risk of suicide or self-harm, and that these situations appeared to be due to a lack

of suitable emergency placements. The Children's Mental Health Coalition has also identified that a key challenge to providing high quality, accessible mental health services and supports is inadequate inter-agency communication and collaboration. A small survey conducted by the coalition in two areas identified 24 different agencies involved in supporting the mental health of children. Co-ordination is a challenge between CAMHS and adult mental health services, mental health and primary care services, mental health services and Tusla, and between schools and mental health services.

Particular groups of children, such as children in the care of the State, children with a co-morbid diagnosis of mental health and intellectual disability, homeless children and children and adolescents with a dual diagnosis of mental health difficulties and substance misuse have seen little development of services to meet their needs. The gaps in child and adolescent mental health services and supports extend further, including a lack of capacity at primary care level to appropriately detect, refer and care for children with mental health difficulties and the absence of a national counselling service for children.

The Children's Mental Health Coalition believes that measures can be taken to improve mental health supports for children and adolescents. The coalition is of the view that in order to improve access to child and adolescent mental health services a national-level approach to inter-agency collaboration is required between Government Departments and agencies. This is particularly relevant for CAMHS and Tusla, as reflected in the report of the task force on the child and family support agency.

Better systems of co-ordination are also needed between schools and primary care and specialist mental health services. The coalition has consistently heard of difficulties that teachers face when they are concerned about the mental health of one of their students in terms of getting advice from CAMHS, referral into services and follow-up after the student has received mental health services. Specialist services for at-risk groups of children and adolescents, including those groups just mentioned, must be developed as a matter of priority. Given that figures for suicide in Ireland among young males aged 15 to 19 years are particularly high by international comparisons and that rates of self-harm in Ireland are highest among the younger population, it is imperative that appropriate crisis services are made available throughout the country for children and adolescents. The coalition has previously called on the HSE to ensure that all community child and adolescent mental health services provide a specialist out-of-hours and crisis service that is well publicised, fully staffed and resourced to provide a rapid response.

A Vision for Change recommends that children and their families are provided with appropriate opportunities to give feedback on their experiences and to influence developments within the mental health services. At present, guidance for CAMHS on enabling children to participate in decisions regarding their mental health has been included in the recently published standard operating procedures. In keeping with A Vision for Change and with the UN Convention on the Rights of the Child, such guidance must be implemented as a matter of priority across all services

The absence of a national advocacy service for children and adolescents accessing mental health services is also of fundamental concern. Advocacy supports must be made available to all such children as a matter of priority to ensure that some of our most vulnerable children can have their voice heard. There is no doubt that the lack of staffing in CAMHS has contributed to many of the shortfalls in service provision. Information provided by the HSE to the Children's Mental Health Coalition last week confirms that the number of clinical staff in post in community child and adolescent mental health services is 505. This represents only 50% of the staffing

level recommended in A Vision for Change. It also represents a decrease of 16 clinical staff in community CAMHS since December 2014.

In May 2015, the CAMHS in Waterford stopped taking referrals and appointments due to the absence of a consultant psychiatrist and difficulties in recruiting a consultant to the vacant post. Despite efforts by the HSE to recruit staff to CAMHS, this is proving largely unsuccessful to date. 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.

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

Chairman: I thank Ms Mitchell for her very interesting presentation. Mrs. Nugent, wife of Professor Kevin Nugent, is in the Visitors Gallery. She is very welcome to our meeting this morning. It is good to have her here. I now call on Deputy Colm Keaveney who is representing Fianna Fáil.

Deputy Colm Keaveney: I thank Professor Nugent and Ms Mitchell. It was inspired to combine a strong medical aspect and a process aspect in the discussion. It was an important mix. What jumped out at me in Ms Mitchell's presentation was the issue of gaps in services. It appears that the current policy, A Vision for Change, which will be ten years old next year, was not resourced adequately to achieve the transition from acute, long-term care in institutions with high walls and lock-up keys to the virtual ward in the community. The policy of filling those gaps based on natural wastage was retrograde. We have a transition from long-term residential care, during which we are waiting for a whole time equivalent, whether it be a domestic security man or woman or a gardener that will not be recruited to underpin the transition into the primary care team until someone reaches the age of 65. A policy, A Vision for Change, which provides for primary care - the virtual ward in the community - was rolled out, but it will not be resourced adequately until someone retires from the old system, at which point someone is recruited into the new system. It is at that point that there will be targeted investment into the team. A total of €35 million was provided for it in the programme for Government. We will not go there because from the previous comment on the investment in primary care, the team itself would appear to be significantly short of what was set out in the policy.

I thought Professor Nugent's contribution was wonderful.

Professor Kevin Nugent: I thank Deputy Keaveney.

Deputy Colm Keaveney: It underpins the seriousness of early intervention. Does he believe there is a role for the introduction into the education curriculum, either at preschool or in the early school years, of cognitive behaviour therapy, CBT? That would be one area to develop in terms of some self-awareness for children to recognise the source of issues that arise. Professor Nugent's description of the early influence of external factors point to the significant role of the economy, job insecurity, quality of home and community. That has an important role to play in this country, which is a perfect example of a relatively small society that has had a significant impact from the collapse of the international market and its impact on the individual and the community.

My final point relates to the chronic lack of an appropriate, acute residential unit for children experiencing self harm or a holistic safe location for mental health supports. When children are placed on adult wards it becomes a lifelong stigma for the child. Could Ms Mitchell provide a progressive analysis of the shortcomings in the service, where we need to provide more, what the policy is and whether it is being fully implemented?

It is very difficult to measure or benchmark key performance indicators in the area of child and adolescent mental health services. It is also difficult to say, in the context of the provision of €35 million to secure transparency on per annum current expenditure in that area, that it is not a case of €35 million, as the amount builds every year in current expenditure. In year 2 it is €70 million and in year 3 it is €105 million. If the money is not spent at all it is not just a case of €35 million that is not being spent. What is the consequence, in particular in the area of capital expenditure of the chronic lack of child and adolescent mental health beds in an acute residential setting? How many beds do we need and what is the level of urgency in the area?

Deputy Caoimhghín Ó Caoláin: I join with you, Chairman, in welcoming our panel before us this morning. I might be a little bit provocative in teasing out some of the points made by Professor Nugent. I very much appreciate the thrust of all that has been outlined both by Professor Nugent and Ms Mitchell. However, what strikes me is that it is almost like a fire brigade response. It is a case of focussing where the problem presents, and setting out the responses we need and that we must develop and provide rather than trying to address the problems before they might even present.

I scribbled a note for myself. I cannot speak for other churches as the only one of which I have personal experience is the Catholic Church. It insists on pre-marriage courses. I have no doubt that is verified, but surely pre-parenting courses in whatever setting would be at least of equal importance, and in my opinion of even greater importance. It is not a part of any of the preparation. I speak as a parent of five children. Listening to both speakers and all they have outlined made me think back on what prepared me for the role of becoming a parent. It was almost just a case of it being something that would happen, yet before the church would even permit access it insisted that we would hear its views on how we might cope with the stresses and strains of the compromise of married life. I am not different to anybody else; I am sure becoming a parent has been one of the most challenging new realities in the life of any young adult.

Professor Nugent said that during the first three years of life children's long-term capacity to think, understand and solve problems, etc., are in their most crucial developmental stages. He spoke of "we". As a public representative and parent I am trying to say I am sorry, I just did not know. I thought Deputy Keaveney would touch on the issue when he spoke about the education system, but more than just in terms of the point he made, I do not know of any other structure that will address future parents, the most important role anybody could be entrusted with in life, other than the school system. This is at least as important as any other academic course that might present either in primary, secondary or even third level education. I am trying to tease out the subject with the witnesses to find out if they have a view. Do they think the knowledge that has been imparted to us in the short opportunity both witnesses have had should be made more widespread? That is not happening in the school system. Nobody is saying what we know. Expert opinion must become societal knowledge. There needs to be a critical understanding and awareness. I am not responding specifically to the points that were made; I am trying to look beyond that and to broaden out the platform of responsibility because we need to get to a point where all young children are given the maximum prospect of a fulfilling life.

Chairman: Time, please.

Deputy Caoimhghín Ó Caoláin: Could you be a wee bit kinder to me just for a moment, Chairman? I will take all the time of my colleagues who are no longer present.

Chairman: Unfortunately, there are others indicating.

Deputy Caoimhghín Ó Caoláin: I beg your pardon, Chairman. I will leave that point with Professor Nugent. I am very interested to hear how he will address it.

I will move on to Ms Mitchell's contribution. I am sorry to have been a little long on the first point. I wish to focus on the gaps that exist within the infant mental health area. The incidence of stopping referrals and appointments in CAMHS in Waterford, the inability to recruit in Sligo and Leitrim and the fact that current staffing is only 50% of what was recommended in A Vision for Change are all serious issues. The Waterford and Sligo and Leitrim situations seem to both be hung on the hook of the absence of a consultant psychiatrist. My understanding is that Dr. D'Alton is not a psychiatrist; he is a psychologist. Are we locked into the need for the medical and psychiatric area? Is it a fault line in the system that such experts cannot be recruited? I have met many eminent psychologists and they have been of much more help to me and many others than those in the field of psychiatry. I mean no disrespect but is there a way of dealing with this? The witness is talking about additional measures and a more creative way of using existing staff but what I am trying to explore is whether there are perhaps other answers that would allow us to bring the child and adolescent mental health services, CAMHS, up to the level that we clearly need.

Deputy Mary Mitchell O'Connor: I will reflect Deputy Ó Caoláin's comments, as parenting is all there, even before a person has a baby. There are prenatal classes and one person in the organisation can really help, which is the district nurse. District nurses go to families after the birth of babies. I have spoken to district nurses and they tell me they can see the problems immediately. We need to get back to that. I am speaking from the experience of being a school principal in charge of 620 children from age four upwards. Correct me if I am wrong but there seem to be more children presenting with issues than there have been in the past. Is that because of the pressures of life? I do not know.

I had the experience of helping a young person admitted to a well-known psychiatric service in Dublin. It was a residential service and every night I went to visit the young adult different staff were working. I was the liaison person but I could not speak to the same person one night after another. There would be round-table family conferences and they would always involve different staff. I found it very difficult to sit and watch what I thought was a service that was not good enough. This occurred in the past and it was not during this Government's tenure.

I visited a school principal recently in my constituency in Dún Laoghaire to discuss cyberbullying in a girls school. While attending the meeting, the principal told me it was not cyberbullying at all but self-harm. At the end of the contribution, the witness indicated that 147 girls in the 15-year-old to 19-year-old age group presented to hospital as a consequence of self-harm. I know the parents of some girls whose children seemed to be capable, with everything fine in the home, but they were affected by this. Will the witnesses tell us what is going on in society? Will they advise parents on the first port of call in such an instance? There is no point giving out and criticising because when parents want help, where can they go and what is the best advice? Perhaps sometimes it will not involve psychiatric services and a parent should be able to sit down and advise a child. Perhaps it might involve a sibling, aunt or uncle. What is

the best approach? I am not so sure the best action is to run off and look for a psychologist or psychiatrist; sometimes, a solution rests within a family. Parents - like many of our parents - might sit down and talk children through their issues and problems.

Deputy Dan Neville: I welcome the presentations from the attendees. With regard to investment, we have been informed that €35 million extra has been invested each year, except for one year when €25 million was put in, over the past five years. That represents an increase next year of €165 million extra every year, as recruited people must be paid every year and introduced services must be provided every year. It is not as simple as having €35 million and giving another €35 million. There will have been €165 million put in after the last budget. Every time we ask questions on the number of people recruited, we are told there are difficulties relating to access. We want to recruit approximately 1,100 people into the area, including CAMHS. People have mentioned that some of the investment has gone into CAMHS so perhaps we can get a handle on what developments have taken place because of the investment.

There is a difficulty in that beds are vacant while children are in adult facilities. It is a real difficulty. I come from Limerick and if somebody there needs child inpatient care, the family must go outside the area. Parents are often inclined to say that they want to visit their child every day and cannot do it if the child is in Dublin, Cork or Galway. The same applies for Donegal. How does somebody in Donegal visit a child of four, five, six, eight, ten or 12 in a hospital when a parent feels his or her presence is very important to the child's recovery because of their relationship?

The witnesses spoke about out-of-hours services but going back ten years, there were no out-of-hours services for anybody. There is a level of service now. Is it still confined to 8 a.m. to 5 p.m. on weekdays? There are certain areas that have expanded the service to weekends. What level of out-of-hours services are there now for child and adolescent psychiatric services? With regard to self-harm, we know the largest cohort of females is in those aged 15 to 20, and for men it is for those aged between 20 and 25. It is a young person's issue. Each year, there are approximately 1,100 admissions to accident and emergency services related to this. Two eminent people are involved in the area, Professor Ella Arensman, president of the International Association for Suicide Prevention and director of the National Suicide Research Foundation in Cork and Professor Keith Hawton in Oxford, and they have stated that for every person who attends a psychiatric unit having self-harmed, there are at least eight who do not attend. Those people either go to their doctor or, because of stigma, which is another issue, conceal it within the family. Some do not even report it. If we are to extrapolate from those expert figures, it means more than 60,000 people of all ages are self-harming every year although it is predominantly a young person's issue.

We are still severely under-resourced in mental health services, going back decades or perhaps centuries. We still have less than 6% of the total health budget going to mental health services. England and Scotland put 13% of the budget into these services and Wales puts in 18% of its budget. We have a big hill to climb in providing proper mental health services for children and adults in this country.

Senator Colm Burke: I thank the witnesses for the comprehensive and detailed presentations this morning. Many of the points I wished to mention have already been raised and I will not go over them. Ms Mitchell gave a very comprehensive presentation on staff shortages and the difficulty with recruitment. Is information available as to why we are finding it so difficult to recruit? Is it a shortage of people with qualifications or is there a problem with salaries or structure? What issues have been identified in the difficulty in recruiting? This takes in medical

practitioners, consultants, junior doctors, nursing staff and social workers. Have the reasons for these difficulties been identified? It has been suggested that we have met just 50% of our staff target. What would happen if we wanted to recruit the other 50% in the morning? Obviously, we would have difficulties in certain areas. The witnesses might refer to the key areas where we are having difficulties.

Do we have difficulties in different areas because of management structures? Is there a problem with the management and with who is in charge? Has that been identified? This is very important. The Chairman and I are aware that great progress has been made in one part of a health area, but there is significant resistance to change in the adjoining area. The issue of change is relevant because we are changing our approach to many areas. Have the witnesses found that there is resistance to change from people who are already in the service? Have we identified a way of dealing with that issue? I am raising this issue because I do not think we can provide a service unless the necessary personnel are available. If we are having difficulty in getting personnel, we should look at the reasons this problem is arising.

The committee received a presentation on young people earlier. Professor Nugent spoke about the need to support children at a very young age. When we speak about supporting young children, we are usually talking about the mother and the father. If a mother who is on her own is not getting any support from her immediate family, does that have a knock-on effect on the child? Has any research shown that there is a knock-on effect? How can we work to provide support to a mother who finds herself on her own? How can we help her to give her child the same support and the same chances as any other child who has full backing and full financial support? It is an interesting issue that Professor Nugent might touch on.

Professor Kevin Nugent: Should I address all the questions that have been asked?

Chairman: Sure.

Professor Kevin Nugent: I will begin by responding to Deputies Keaveney and Ó Caoláin. My perspective is that everybody who comes into contact with the child - the dentist, the carer, the teacher or the occupational therapist - should be informed by mental health philosophy and understanding. We need an informed but compassionate understanding of the needs of children and families. I think it was Deputy Neville who spoke about the importance of parent education. It is really a question of supporting parents more than anything else. The issue of isolation is a key one in this context. This is also relevant to the last question I was asked. As far as I can see, our target is not to give parents brain-based programmes to make their children smarter or better. It is far from that. It is all about relationships. If the relationship is not there, nothing will happen. Learning cannot take place outside the context of a relationship in which the child feels safe, secure and loved. Only then will a child go into the world, explore it intrepidly and be ready to learn with a sense of openness. Regardless of whether we are talking about a school setting or a community setting, our feeling is that the key issue in the first three years is parent support. People who work with families need to be non-judgmental and culturally inclusive. As Deputy Ó Caoláin said, this is not happening in the school system. I want to pull out the cultural capital that exists within families, regardless of their cultural backgrounds, by giving them a chance to express themselves with their children. All parents want the best for their children.

I agree with the point that nurses have a key role from a cultural perspective. I was delivered by a midwife. These people have a marvellous role to play, and it is a role that has been attached to them for many years. All of us need to acknowledge that children can be helped. I will give an example. I saw a six week old baby with all the symptoms of depression. It was

a remarkable case because when I met this baby on the first day of her life in a hospital not far from here, she was responsive and available. I said to the medic who was with me that the baby was having such a good start in life. She was bright as a button. She was tracking and looking around. She was ready for action. When I saw her again six weeks later as she was being placed for adoption, she was unrecognisable because of whatever had happened in the meantime. She had really lost her zest for life. She had poor tone and she was crying all the time. She was almost inconsolable. Of course, this is absolutely reversible. The key thing for the child was to find a relationship with somebody who unconditionally loves her. That allowed the child to reclaim her initial zest for life and her biological expectation that her needs for food and love will be met.

It is certainly true that the earlier we can get there, the better. We feel that these interventions should involve supporting parents more than anything else. They should be family-centred and community-based. As many members have pointed out, the focus should not be on the individual parent. Isolation is really the enemy. Senator Burke asked whether there is any data in this regard. There is data all over the place. For example, a premature baby who is isolated is more likely to have all sorts of issues. Isolation is even more important than social class. The absence of support can be a problem. It has been mentioned that it is important for mothers to have other women to talk to. I really want to support that whole issue. My focus is on prevention. Ms Mitchell is dealing with critical things like young people self-harming. I am saying that we should be seeing the signs right at the beginning. We should look at whether there are mental health issues in the first three years. Luckily, people like Dr. D'Alton are looking at this. The Irish Association for Infant Mental Health is training professionals to be aware of this. One needs to have very good eyes to see that children are showing the signs of trauma, but it can be done. We do not want to believe that very young children notice what is going on. I used to say that they do not notice, but I know now that they notice everything. The six week old who was mentioned noticed that the world was not there for him. He was fed, but he already realised that his biological expectation and need to be cared for was not being met. By that time, he had internalised a model of the world as a world that is not there for him. Our goal is to support the development of trust and of the expectation that the world is going to be there for children and is going to support children.

I will conclude by summarising what I have said. I hope I can address all of the concerns of members by saying that this is an issue of prevention at an earlier stage. The human brain is at its most malleable in the first three years. I remind the committee that this is a case of "use it or lose it". If a child gets positive reinforcement from his or her parents, all the architecture of his or her brain will be framed by that. By the time he or she goes into school, he or she will be ready to learn by virtue of what happened before his or her third birthday. If a child is secure, he or she will not have to prove anything and he or she will be ready to explore. By contrast, the anxious child who does not feel a sense of being valued and loved in the early years will have great difficulty in school. All I will say, following the work of Dr. D'Alton and others, is that we should be there at the very beginning. If we were to ensure all professionals are given mental health training when they enter the profession, we would deal with one of the key issues that presents itself.

Ms Kate Mitchell: I will do my best to try to answer the committee's questions as comprehensively as I can. If I miss anything or if members have any follow-up questions, I ask them to come back to me.

Deputy Keaveney asked where we are at, and where we are going, with regard to A Vision

for Change and its resourcing. The first thing we need to address is the huge challenge that is being faced in the recruitment of mental health staff. I refer particularly to child and adolescent mental health services. We know the HSE has been driving international recruitment campaigns. The number of people applying for nurse and consultant mental health positions, including child and adolescent mental health positions, on foot of those campaigns is relatively low. I will say a little more about that when I respond to Senator Burke's questions.

Another matter we need to look at is the recognition of some underdeveloped areas since the publication of A Vision for Change. There have been commitments to invest in the area of eating disorders for children and adolescents. We know this service will be part of the new children's hospital and that training for mental health staff in the area of eating disorders for children and adolescents has progressed this year. However, other areas of need have been somewhat overlooked, including, for example, mental health and intellectual disability. In A Vision for Change, approximately 15 teams were recommended to be dedicated for mental health of intellectual disability and yet we only have approximately four MHID posts in place. That is a significant issue. There is also the question of children and adolescents presenting with issues of dual diagnosis of mental health difficulties and substance misuse. Anecdotally, we hear stories from organisations and families to the effect that they experience major difficulty in accessing the mental health supports that children and adolescents require. A Vision for Change recommended that there would be two dedicated teams to address these issues but we have not seen the establishment of those teams. We still have a way to go in terms of developing specialist services, some of which have received little attention since the publication of A Vision for Change.

There is also the issue of developing capacity in other areas such as primary care. At the moment, there are major concerns to the effect that the capacity simply does not exist to detect mental health difficulties and refer patients appropriately. This even extends to concerns over awareness of other community mental health supports that may be of benefit to children and adolescents. The area needs significant investment and attention, as do other areas such as out-of-hours crisis services.

Members referred to the monitoring of what is happening in terms of service provision relating to mental health outcomes for children and young people. The standard operating procedures for child and adolescent mental health services, CAMHS, was published some months ago. These were developed for inpatient and community CAMHS. This was a major step forward in trying to standardise service provision for children and adolescents. We know that one of the bigger concerns is the variation in service provision for children and adolescents in accessing services throughout the country.

One of the questions is what should happen next. There needs to be implementation of these standard operating procedures throughout the country in all mental health services for children and adolescents. This is something the Children's Mental Health Coalition and Mental Health Reform will be keeping a close eye on. There is also a need for a system of monitoring appropriate outcomes. This has been recommended by the World Health Organization and is in line with international good practice. This is something the Children's Mental Health Coalition has been advocating. It is most important.

Deputy Ó Caoláin asked a question about early intervention. The area-based childhood programme is funded by the Department of Children and Youth Affairs. It contains elements of mental health promotion and, at a local level, specific ABC programmes in certain areas have specific mental health programmes within them. However, we recommend that there should

be a national roll-out of these. Moreover, there needs to be clear recognition of mental health components within early intervention programmes.

Chairman: At one level, Deputy Ó Caoláin's point was probably the most apt one we have heard this morning and he is right. Anyone who wishes to get married in a particular church has to do a pre-marriage course. However, as far as I am aware, there is no stipulation for a couple to go to pre-parenting classes. Deputy Ó Caoláin made a good point. Sometimes when people are presented with a gift, they have no skills to manage. We can have all the programmes we like. Is that not the case? Deputy Mitchell O'Connor made reference to this as well.

Deputy Mary Mitchell O'Connor: I did not come at it from that slant.

Chairman: I know, but I am referring to what Deputy Ó Caoláin said in terms of parenting. I spent 17 years in a classroom. I knew who the good parent was - the parent who had the skills and capacity - as well as the bad parent. The point is valid.

Deputy Mary Mitchell O'Connor: They are not bad parents.

Chairman: No, but there are parents who do not have the ability, for whatever reason, or who are not equipped.

Deputy Mary Mitchell O'Connor: There are different times in a parent's life when he or she might have pressures. One cannot call them bad parents.

Chairman: Deputy Ó Caoláin's point and my point relate to how to empower people to become a better parent. That is the point, perhaps.

Ms Kate Mitchell: We know there are programmes in existence, for example, the Preparing for Life programme in Coolock. It is a very positive programme. Certainly, we advocate that there should be a national roll-out of such programmes and that programmes should be made more widely available.

I referred to the national guidance on promoting mental health promotion and well-being. Guidance has been published for primary and post-primary schools. The Children's Mental Health Coalition very much welcomes the guidelines. We are concerned about their implementation. To ensure the translation of the guidelines into action, there needs to be appropriate resourcing and training of teachers.

Deputy Ó Caoláin referred to the absence of a psychiatrist within CAMHS teams and how, at times, this can lead to new referrals not being made as a result. Dr. D'Alton may be able to answer the question better but it seems that in the majority of teams, the psychiatrist remains the clinical lead. We know of some CAMHS teams where that is not the case. In those cases the lead may be a nurse or a professional from a different discipline. Anyway, that needs to be looked at. The question is whether the psychiatrist should be the lead and how to integrate other professionals into the role. We have heard of cases where children who access CAMHS may need referral to a psychiatrist later. There are concerns over referring or admitting a child when, it transpires later, the child requires psychiatric input. That issue needs to be examined for future reference as well.

Deputy Mitchell O'Connor raised the question of where parents need to go for support. From the bottom up, we advocate the one-good-parent or one-good-adult model. This is something Headstrong strongly advocates and recommends. The ethos is that every child or adoles-

cent should have one good parent or one good adult who he or she can talk to and for that person to listen to his or her concerns.

There is also an issue over having capacity built up across the mental health system. A Vision for Change recommended the need for capacity across the continuum of mental health care from primary care level to specialist support services. This goes back to what Professor Nugent said. He referred to the need to capture mental health difficulties before they develop. There is a place for mental health promotion at the earliest stages from perinatal and infant mental health right up to child and adolescent stages. There is also the question of building capacity at each level through primary care. If a family member, child or adolescent goes to the doctor, then the doctor has the capacity to refer the patient or intervene or provide care. However, there must also be clear referral points into specialist services as well.

We need to see the development of lower level community mental health supports. We have seen the establishment of Jigsaw programmes and the benefits they bring to a number of children and adolescents. This is something the Children's Mental Health Coalition strongly advocates for. We need to see development of more lower-level community mental health supports and alternative supports to specialist services.

Chairman: Deputy Byrne is keen to come in and I am mindful of the time.

Ms Kate Mitchell: I will finish quickly. Deputy Neville referred to vacant beds and a lack of inpatient beds for children and adolescents. We know that from March 2015, there were 58 child and adolescent inpatient beds available out of a total bed complement of 66 but A Vision for Change recommended 108 inpatient beds. This is something about which we are very concerned. As I mentioned previously, there is a need to develop capacity along the continuum of mental health care for children and adolescents, including through primary care and lower level community supports. However, it is also very important to recognise that there is a need for specialist inpatient services. The recent annual report from the Ombudsman for Children highlighted this as a key concern and argued that the provision of such inpatient beds is extremely important.

Senator Burke mentioned recruitment and, as I pointed out to Deputy Keaveney, there are enormous difficulties in the recruitment of staff, particularly for CAMHS, despite efforts by the HSE, including international recruitment campaigns. One of the main issues in that regard is that we cannot compete with our international competitors. Overseas recruitment packages seem to be much more attractive and we may need to examine the remuneration packages we are offering. Another issue is that mental health professionals do not want to take up a position within a team when they already know that the team is under-resourced and underdeveloped and that they are going to be under significant pressure and may not be able to deliver the type of service they want to deliver in order to support children and young people appropriately. There is also an issue around training for CAMHS staff. Such training must be adequate because of the complexity of the area. Staff are dealing with individuals who have mental health difficulties and who are particularly vulnerable by virtue of the fact that they are under 18 years of age. Appropriate training is extremely important.

Deputy Catherine Byrne: I apologise but I had to go to the Chamber to speak on a particular matter. I read Professor Nugent's submission at length last night and in all of my time as a member of this committee, I have not read a more interesting or moving presentation. It highlighted our responsibilities as citizens but, more particularly, as parents and grandparents to children. I was reminded of my own mother, who was my mentor in many ways. She always

said that children are like sponges and that we must be very careful about what we say in front of them because they absorb so much. She also had a very common sense approach to many issues, similar to that of Professor Nugent, including how we look at children's lives, the environment in which they live and how they are reared.

I took part in a parenting course in the school attended by my children not because I felt that I was a bad parent but because I hoped it would enable me to work with other parents and learn about how they dealt with difficulties. Being a mother for the first time can be very stressful. A lot of issues arise, some medical and some more basic, like having a baby who is very cross at night and so forth. It was wonderful for me to be able to avail of that parenting course. However, often parenting courses do not reach the people who really need them. Some parents started the course I was on but only stayed for a week or two before dropping out. In my opinion, they were the parents who needed it most. I am not saying I was perfect but there were others who definitely needed it more than me.

The professor spoke about stability, which is so important. A gynaecologist once told me that babies in the womb can hear and feel. They can also feel anger and aggression. Babies in the womb are not isolated from what is happening in the world but are very much part of it. Unfortunately, we do not live in a perfect world or in perfect communities. A lot of children do not live in perfect families, which is what this document is all about. As public representatives, we must deal with that.

I firmly believe that sometimes the only way to deal with people who cannot be the parents they need to be is to deal with them first. A lot of people who have babies are not prepared for parenthood. That can be as a result of their own family background. When I was pregnant I knew that I could reach out to my best friend, parents, husband and extended family but some women do not have that support and that is where early childhood problems start. We must focus on this if we want to deal with many of the issues raised by Ms Mitchell.

Ms Mitchell said that the figure of 870 clients, or children, was reduced to 241. Does that figure represent children caught up in the mental health system for more than 12 months? Ms Mitchell also referred to an inability to keep staff or to get staff to come on board. Will she outline the reasons for this, other than emigration? I know of a case involving a beautiful young man who has an intellectual disability. He has Asperger's syndrome, autism and is non-verbal with violent tendencies. His parents are at their wits' end. They are jumping through hoops and I am jumping with them, to be honest. Sadly, the only thing that has been offered is a long-term care placement in Monaghan but his family lives in Dublin. His mother does not drive and would have to travel by bus to visit him. His father is self-employed and cannot take much time off.

We need to take children's mental health seriously, from the womb right through to secondary school, because if we do not do so, the consequences can be dire. Deputy Dan Neville has been a strong advocate for suicide prevention. If we do not address mental illness in children and adolescents, our suicide figures will not decrease but will increase. The Government and all public representatives must ensure that the next generation of children in this country do not end up in the current mental health system. I give the witnesses a commitment that I will do anything that I can to highlight these issues within my own party.

Chairman: Deputy Seamus Healy is next.

Deputy Seamus Healy: I want to apologise for my absence earlier. Unfortunately I was

otherwise engaged. I welcome the presentations and, like Deputy Byrne, I found Professor Nugent's presentation one of the most striking and informative I have ever read. The professor puts huge emphasis on early intervention, family support and community support during the first three years of a child's life. He refers to the difficulties arising from isolation and the absence of support. Could Professor Nugent outline the practical steps that can be taken in that regard?

Professor Kevin Nugent: If it is not a bit self-promoting, one of the things I did with some of my colleagues was to develop an approach to working with new mothers and fathers in the perinatal period. Even though I have spoken of the importance of the first three years, we have found that the first three months are critical in the formation of a family. If we intervene at that point, we can help parents to understand their own child as an individual and to realise that their baby can be a therapeutic agent in their own recovery in, for example, the case of a single mother who is on drugs. There is a chance for a psychological rebirth and the baby becomes the key person. My research over the years is that one is giving the baby a voice through reading the baby's cues as a way of getting an assessment of who this baby is.

Prenatally, we have had many groups and I felt my contribution was actually minimal. People want to talk to each other and to normalise the experience of pregnancy. Isolation is very often the enemy. In the first three months, for example, the goal is to be there with them through home visiting, such as the visiting nurse Deputy Mitchell O'Connor talked about, and being there with them over the first three months to develop the foundation during this huge family transition when, in all cultures, the boundaries are quite permeable. People can enter and one can be part of the family story, as a nurse, professional, a home visitor or early intervention provider, by being there to support the parents at that time. That is just one example, but it is very much strength based. There is never an attempt, even in the case of the 15 year old single mother on drugs, to label the mother, but to try to give her the support she needs to become a mother for this child. As I said, often the baby becomes the catalyst for change.

The same applies to the high risk infant, the baby who was born prematurely and the expectation that a high risk baby brings. How do we support parents with that? One of the initiatives we have, and I am happy we developed it, is an infant-focused but family-centred model of care that is embedded within the community. Again, understanding the inner life of the baby becomes the catalyst for change and then there is fostering the relationship along the way. The basic belief is that there must be a secure relationship, whether it is the mother *per se* or any alternative care giver. The key thing is the child must feel valued, worthy of trust and worthy of love, so that by the end of the second year of life the child has that individual sense of self and a sense of being valued as a person. That would be our goal, to create a sense of trust and a secure attachment relationship over the first two years of life.

Our approach has been, and there are many ways one can do it, to begin in pregnancy but around the perinatal time of transition to becoming a parent to be available there, supporting that and having the baby as our catalyst for change.

I hope that was helpful.

Dr. Paul D'Alton: Briefly, reflecting on the conversation we had this morning, Kate mentioned the concept of one good adult. We can summarise decades of good scientific research and say that a child will do okay if there is one good adult in his or her life. It is our job as mental health experts and as citizens to ensure that each child has one good adult in his or her life. This is a systemic problem and it requires a systemic response. Professor Nugent presented the

biological evidence for what we all know and for what is common sense, that it is the start of our lives that matters. My mother says it constantly: "Sure he did not have a great start." We know this and we have the evidence to support it.

It is also important to point out that we must be very careful about the message we give to parents. I constantly say to parents that it is the 70:30 rule. If one is getting it right 70% of the time, that is good enough. We are not looking for perfect parenting. The 70:30 rule is good enough.

The other important point, and several speakers raised this question, is the impact of austerity and disadvantage. Professor Nugent and I have talked several times and summarised it many times by saying that equality is the best therapy and the best intervention we can provide to ensure a stable and flourishing society, beginning with the infant mental health of our youngest. Infant mental health is everyone's business. I have said this about palliative care. Palliative or end-of-life care is everyone's business, and infant mental health is everyone's business. It is not the business of a psychiatrist, psychologist or a nurse. It is everyone's business. If we do not get that right we will cause untold damage and suffering for generations to come. It is everyone's business.

This can be actualised and implemented through a programme we developed on palliative care. We developed a palliative care competency programme, which is a competency based programme for the training of health professionals across the board. This sets out what health professionals need to know about palliative care. We can do the same thing with infant mental health. The important thing about that is that it feeds directly into undergraduate and postgraduate training.

Chairman: There is a vote in the Dáil so perhaps you could conclude. We will finish this session in approximately three minutes.

Dr. Paul D'Alton: The importance of education for the health care providers is that it is based on the idea that what every child needs is one good adult.

Chairman: Does Ms Mitchell wish to add to that?

Ms Kate Mitchell: No. As a closing remark, I wish to point to the importance of an inter-agency and interdepartmental approach on improving the mental health outcomes of children and young people. There is currently a protocol in place between Tusla and CAMHS but we must see this translated into action. We must see our most vulnerable children getting access to the mental health supports they need.

Professor Kevin Nugent: I wish to pay tribute to Dr. D'Alton and to Ms Catherine Maguire, former head of the Irish Association for Infant Mental Health, for the work they are doing. As Dr. D'Alton said in a great phrase, infant mental health is everyone's business.

Chairman: On that positive note, we will suspend the sitting until after the vote. I sincerely thank Professor Nugent, Dr. D'Alton, Ms Kate Mitchell and Ms Lara Kelly. I thank Lara, in particular, because she has been a strong advocate to us in this committee and to the Oireachtas on mental health.

Sitting suspended at 11.20 a.m. and resumed at 11.55 a.m.

Challenges facing Camphill Communities of Ireland: Discussion

Chairman: I ask all those present to switch off their mobile telephones. I welcome the delegation from Camphill Communities of Ireland to the second session and apologise for the delay. The number of votes called in the Chamber this morning suggests parliamentary democracy has gone into overdrive. As members and those watching and listening at home will be aware, Camphill Communities of Ireland provides support services to people with special needs. I welcome from Camphill Communities of Ireland, Ms Miriam Moffitt, Mr. Joe Lynch, Mr. John O'Connor and Ms Anne Finn and thank them for making themselves available for this meeting.

I draw the attention of the witnesses to the fact that by virtue of section 17(2)(l) of the Defamation Act 2009, witnesses are protected by absolute privilege in respect of their evidence to this committee. However, 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 are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person, persons or entity by name or in such a way as to make him, her or it identifiable.

Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside the Houses or an official, either by name or in such a way as to make him or her identifiable.

I invite Mr. Joe Lynch, national governance co-ordinator of Camphill Communities of Ireland, to make an opening presentation.

Mr. Joe Lynch: I thank members for inviting us before the joint committee. After more than four decades of providing a unique and successful type of support to people with special needs, Camphill Communities of Ireland is facing the real prospect of having to cut its services for the first time. There is even a question mark hanging over the future of the organisation's operations. Camphill Communities of Ireland serves more than 275 people across a range of ages, most of whom are full-time residents in 17 locations. Funding issues with the Health Service Executive, which remain unresolved despite negotiations dating back to 2004, threaten the sustainability of the Camphill model under which the organisation provides secure home environments for residents in its urban, suburban and rural locations nationwide. If these issues are not resolved, there is a real prospect that many of the 275 people served by the organisation will have to transfer to care organisations that are considerably more expensive to the State and do not provide the unique volunteer-based, life-sharing model of Camphill.

Camphill Communities of Ireland is now very frustrated at what it sees as a stonewalling attitude in the HSE towards dealing with this ongoing and protracted situation. At a national level meeting in December of last year between the HSE and a delegation of a number of people from Camphill Communities of Ireland, it was stated bluntly that one community simply could not survive past 2015 without additional funding. To date, very little has changed. In that particular example of an urban Camphill community which supports 20 people with special needs, 16 of those who live there are full-time residents. The recommended funding, according to the HSE's target rates and published in its own value-for-money review of disability services, is in the region of €1.2 million. The funding received is between 49% and 58% of the value-for-money figures. The differences arise depending on whether the recommendations are assessed

on an estimation of support need or on staffing levels, each relating to the residents. There is also a variation when a calculation is made, taking into account a contribution from the disability allowance of the residents. In the example community, when compared with the funding provided by the State in 2008 - which more or less met the needs of the operation - there has been the equivalent of between an 8% to 14% cut in funding since 2009. Camphill is not necessarily asking for the full recommended assumed rates according to the HSE's value-for-money report. It would likely be able to sustain the community at a funding level of between 65% to 70% of the target funding levels highlighted in that report.

The Camphill Communities of Ireland operation is a relatively small component of the matrix of service providers for approximately 8,000 people with special needs in residential services in Ireland. Its principles also differ in that the concept is based on the principles of Rudolf Steiner and are underpinned by the acceptance of the spiritual uniqueness of each human being. When the organisation was established in Gorey, County Wexford, in 1972, almost all of its workers were long-term vocational volunteers known as "co-workers". My colleague, Mr. John O'Connor, is seated to my right and is a vocational volunteer co-worker. Such co-workers lived as part of the community and provided 24-7, family-type care for residents. Modest living expenses are shared and many co-workers have raised their own families within these Camphill communities. They have traditionally been helped by short-term co-workers or volunteers such as students from Ireland and abroad who take the equivalent of a gap year to work with the organisation. Small numbers of local volunteers are also involved. In all three elements there is a large component of altruism. The culture and diversity, not to mention friendship and companionship, that co-workers bring to the lives of people with special needs cannot and should not be underestimated. The vocational volunteers provide a vital and fundamental role within Camphill but sadly long-term volunteers are diminishing.

With 505 people now in the total workforce, the organisation has seen a 9% increase in worker numbers in the past two years while funding has decreased significantly over the same period. Within the total, the number of paid employees in the past six years has increased by 25% and between 2009-2013 wage costs for those employees have increased from €2.4 million to €4.2 million which has placed severe pressure on financial resources that are diminishing.

Virtually all of the organisation's income is from the public purse. When the operation was established, it was paid in the form of initial block grants to meet minimum estimated needs, to be topped up if necessary. In the early 1990s the system was changed to a capitation fee basis, which is a more transparent way of funding. Initially, new funding worked out well even though Camphill communities were typically receiving capitation fees of approximately 50% of those paid to other organisations in the same field. The high altruistic nature and element of those who work in Camphill communities means that the wage element of a community can be as low as 45% of total costs when compared with a typical 80% in more mainstream organisations. It is accepted that the savings to the State from the activities of Camphill communities are currently in the region of €5 million annually.

At present there are 274 co-workers. The number of co-workers has remained fairly constant though the proportion of short-term volunteers is rising. This is partly because it has become more difficult to attract long-term co-workers to the Camphill lifestyle. The situation is exacerbated by the increasing number of long-term co-workers now reaching retirement age for whom a small top-up provision to their State pension has also to be made. On the other hand, the numbers of fully paid employees in the communities has risen steadily. The declining number of long-term co-workers is part of the reason employees will only work more conventional

hours compared with the 24-7 input of co-workers.

Camphill welcomes the efforts to improve the quality of residential care and actively engaged with HIQA throughout the inspection and registration processes which, although challenging, has been a positive experience. In fact, a HIQA inspector commented off the record that if they had a child with an intellectual disability that they would choose Camphill as the preferred model of service. However, Camphill is also meeting greater financial pressures as the regulatory process for residential disability services requires a substantial amount of administrative work, as well as more stringent fire and other safety and infrastructure changes. A significant element of its residential accommodation is now 30 years old or more, which brings extra financial burdens. All of this has also meant that long-term co-workers are increasingly pulled into administrative tasks rather than the life-sharing ethos of the Camphill ideal. In order to address this issue, Camphill has had to support these roles through employment which has led to increased costs.

When the HSE conducted a value for money pilot study, it invited Camphill to participate so that it could address the funding issues. The study found very large discrepancies between the costs involved in the various agencies. Camphill was very much at the bottom end of the list on a cost per resident basis, so much so that it was in part nearly considered an outlier in statistical terms. The pilot has subsequently been rolled into a report on value for money and policy review for disability services. This report came up with a programme to achieve a 5% reduction in annual funding per placement from the 2009 level. Instead of the value-for-money review being used to address the huge discrepancies in the system, Camphill's funding was targeted to achieve the same cost savings as everyone else without the increases in funding that larger service providers had been granted in the Celtic tiger years.

Following many meetings with the HSE, at both local and national level, the delegates of Camphill say that they now feel absolutely frustrated at being ping-ponged from one level of the HSE to another with no movement on the funding issues. Camphill has been informed that the HSE may at some point in the future develop a needs assessment tool to work out the support needs of individual residents. Camphill supports the move as it would bring equity into what is a very skewed system at some unspecified point in the future.

Camphill says it has simply been blocked at almost every turn and, most recently, by the suggestion that a service improvement team led by the HSE, that would consist of individuals seconded from larger service providers, would inspect the way Camphill delivers its services with a view to highlighting how further cost savings could be achieved. Some co-workers have reached the conclusion that they must simply walk away from their vocation. If that happens, the resultant costs per resident will inevitably balloon compared with the very low cost of the Camphill model, even in a modern context of some employed supports. These are swollen costs that the Irish taxpayer will have to pick up. Such a scenario would be detrimental to the individual residents who consider their current Camphill placements home. Equally, the 17 urban, suburban and rural locations in which Camphill operates would also lose out because, in each case, residents and co-workers have integrated into their local towns and villages. Camphill's ethos has invariably resulted in extensive mutual support in those locations and communities have adopted the residents. This is integration in a very real and progressive way that clearly belies the tokenism of some institutional models.

In the face of the current programme of avoidance, Camphill has been forced to undertake a political lobbying exercise to try and bring some pressure to bear on the situation and to break an 11-year logjam. If lobbying does not succeed then a major shift looks inevitable. Such a

shift would mean increased costs for the taxpayer and an undeserved end to four decades of hard work, goodwill and obvious achievements by thousands of voluntary co-workers who are sharing, and have shared, their lives with people with intellectual disabilities. Worst of all, however, is the fact that 275 people who have lived much more successfully than they or their families could ever have expected will face an unknown future and be wrenched from the love and care they have today. Camphill seeks real engagement with the HSE to redress the appallingly low capitation fees that have persisted at Camphill over the past two decades. In fiscal terms three of our communities are close to the edge and soon they will have to commence arrangements to transfer residents to the care of the HSE if a solution is not found in the very short term.

In addition, the rigours of the new regime imposed by the national standards for residential disability services need to be addressed in a very concrete way. Simply ignoring the problem will not aid the safe care of people with special needs. The HSE asked for costings for fire upgrades and other works. The costings were supplied more than 12 months ago. To date, HIQA has inspected all but two of Camphill's communities. The issues identified require substantial funding to meet the requirements of the inspections. To date, no funding has become available. Ongoing maintenance of a huge raft of buildings is not currently included in any funding stream from the HSE. This also does not take account of the financial cost of purchases of new vehicles. A funding mechanism must be found to ensure safe homes and safe vehicles for the people we care for.

Chairman: I thank Mr. Lynch for his presentation. It is disappointing that the presentation shows there is an issue with the HSE. Is it Mr. Pat Healy in the HSE that Camphill deals with?

Mr. Joe Lynch: It is Marian Meany and Pat Healy, yes.

Chairman: Has there been dialogue with them before the meeting today?

Mr. Joe Lynch: We started a dialogue with the HSE in 2004 and with Pat Healy-----

Chairman: I mean in recent times.

Mr. Joe Lynch: We had our last meeting with Marian Meany in February 2015.

Chairman: Was that the last contact the witnesses had with the HSE?

Mr. Joe Lynch: In fairness, we have had contact with the HSE at local level, but we had talks with the HSE in December 2014 and February 2015 and have not had another meeting since then.

Chairman: The reason I ask the question is that I was looking forward to hearing about the successful work that Camphill Communities of Ireland does rather than putting Mr. Lynch in the unfortunate position of having to come to the committee and base most of his presentation on a lack of dialogue and action by the HSE. That is disappointing. I have tremendous time for the work of Camphill Communities of Ireland and what it achieves. From talking to people who use the service, I know it is fantastic. I was hoping that this morning we could shine a light on the great work of Camphill Communities of Ireland. In fact, I hope we can do that during the question and answer session. However, it is why I am disappointed about the presentation. I am annoyed at the fact that there has not been contact with the HSE. I do not want to pre-empt the discussion, but I hope members will agree to write formally to the HSE after the meeting. I am disappointed from the perspective of Camphill Communities of Ireland because I was hoping we would have an opportunity for the organisation to tell the world listening and watching

about the great work it is doing rather than having to come here and, as it is perfectly entitled to do, give a presentation on the issue with the HSE. It is disappointing because Camphill Communities of Ireland does great work.

Deputy Caoimhghín Ó Caoláin: To inject a little more balance, I reflect on my own personal exposure to the work of the Camphill community at the Ballybay location in my constituency and home county. I have had the opportunity to engage with Mr. Joe Lynch previously, including at Ballybay, and I know personally and from my own attendance on a number of occasions at the special days that it is a fantastic facility. I pay tribute to all who give service there and throughout the Camphill communities throughout the country. I have met people whose commitment is a vocational one. I hope Mr. John O'Connor will accept that I see it in those terms and the role as a vocation. There is no other way to describe what is involved and the people I have met tick that box in the most honourable and finest understanding of that idea of vocation. That said, I am sure the situation in Ballybay is replicated throughout all of the Camphill communities and it would be unforgivable if our health system failed to the point that any of these communities were lost.

In his presentation, Mr. Lynch talked about a funding issue with the HSE which has remained unresolved and now threatens the sustainability of the Camphill model. There can be no doubt that if the situation is as bad as that sentence suggests, it is unacceptable. It is not only in terms of the actual prospective loss of any entity within the Camphill communities network; the fact that the threat even exists is unacceptable. I note that Camphill has been told by the HSE that it may at some point in the future develop a needs assessment tool. I do not for a moment believe that is Mr. Lynch's language. The HSE has a great deal to clarify. What does it mean by "may at some point in the future"? It is either going to do it or it is not. It is something that would be more than useful, and I note that Camphill would support that approach. That is one of the questions. I want to record support for, and to second if necessary, the Chairman's proposal that we write directly to the HSE on the back of this engagement. That is one of the questions that should be incorporated in the list of questions that we need to put.

Chairman: I appreciate what Deputy Ó Caoláin is saying. So that members are aware, we got a briefing note from the HSE prior to today's meeting. The Deputy probably saw that. I am glad the Deputy agrees with me.

Deputy Caoimhghín Ó Caoláin: I have chosen to highlight a number of the points Mr. Lynch made in his presentation. He said that individual residents consider Camphill home. There can be no question about that. Among those whom I have met, there is no doubt of that. We are talking about the homes of people with special needs. What that would mean in terms of the individual human beings is inconceivable. We talk about homes and housing in the Houses of the Oireachtas, particularly of late, across a whole range of different situations that have presented. This is just another of those, and these are the homes of people under threat. The alternative is that the HSE would have to take responsibility for the provision of the care settings for the 225 current residents, if I have the number correct. The HSE needs to wake up to what is involved here.

Mr. Joe Lynch has imparted so much information in what he has said. The questions from me are not really back to the panel; they are for the HSE at this point. That said, there are just some points I would like to tease out. Camphill Communities of Ireland was getting capitation fees of approximately 50% of those paid to other organisations in the same field. Would Mr. Lynch like to expand on that? Why has that been the case? What explanation does Mr. Lynch think there is for why Camphill would be treated differently to other organisations providing

services in the same field?

To date, HIQA has inspected all of the sites except two. The issues identified required substantial funding. That is the case as the HIQA inspections have been done and the recommendations are there in terms of care settings for older people. This has required significant investment. Dormitory-style provision is no longer acceptable. At best, one might have a twin-room facility. Most often, people should have their own individual space and all the ancillary services. An effort is being made, albeit not a mighty one, to meet those recommendations in a number of other care settings. To date, however, no funding has become available. HIQA is not out there doing its work just to tick the box. If there are recommendations in relation to specific works that need to be carried out to modernise and upgrade facilities, that is no less the entitlement of the residents in the Camphill Community of Ireland facility. However, the responsibility for funding the works must rest with the Health Service Executive. That is a very important issue, as the HSE cannot ignore recommendations from HIQA. One of the faults in the system is that HIQA does not have the wherewithal to enforce implementation of its recommendations, and Camphill certainly cannot undertake the financial outlay for capital works. It is just not within its gift, and it is the HSE's responsibility. That is another point that needs to be strongly reflected in the communication that I hope we all agree needs to issue from this meeting. I thank Mr. Lynch and his colleagues once again and I wish Camphill every success in its continued service to a very deserving cohort of citizens.

Deputy Seamus Healy: I welcome the Camphill representatives here this morning, thank them and acknowledge the excellent work Camphill does in the 17 centres around the country for 275 residents. I know it does absolutely excellent work in the two centres in south Tipperary, in Carrick-on-Suir and Grangemockler, and I have family connections with some individuals who have availed of Camphill services over the years and found them to be very impressive.

I agree that we should write immediately to the HSE and the Minister, but we should go further and advise both that this issue will be on the agenda of this committee for our next meeting with the Minister and the HSE, which will be held reasonably shortly. This is an urgent issue and I am disappointed that nothing has happened. As Mr. Lynch has said, this has been going on since 2004. Last year, following the presentation given by the witnesses in the AV room, which I attended as did most members here, we made representations to the Minister and the HSE. I hoped there would have been movement on proper funding for Camphill as a result, but disappointment has been felt - both by the representatives of Camphill and by the committee members - that this has not come about. It is difficult to understand the reason. As Mr. Lynch has indicated, Camphill is providing services at approximately 50% the rate of other providers; it is at a discount to the State. If the Camphill centres were to close, the additional cost falling on the HSE and therefore on the State would be significant. That cannot be allowed to happen and I know members will do their utmost to ensure nothing like that happens and that instead there can be real engagement between the HSE, Camphill and the Department, if necessary, to ensure reasonable funding levels are made available.

There are key questions arising from HIQA reports, including the upgrading and maintenance of buildings, the question of new vehicles and funding for the workforce. We have heard about the co-worker element, which is an integral part of the Camphill process. There are probably not as many co-workers or volunteers nowadays as there have been in the past, but we cannot have a position in which the sword of Damocles is hovering over Camphill.

I have a general question for Mr. Lynch. I cannot think why the Camphill communities would be treated in this fashion, but is there any indication of the thinking behind the lack of

funding for and engagement with Camphill by the HSE? I support the case made by Camphill and the Chairman for taking up the matter with the HSE and the Minister. I hope we can do this in time for our next meeting with them.

Senator Colm Burke: I thank the delegation for their presentation. I seek clarification on a few issues as I am trying to get a clear picture of the HSE's involvement. Please do not take this the wrong way, but I need clarification. It was indicated that the number of employees is approximately 500, but I presume not all of these work on a full-time basis. I have done a quick calculation on the money being expended, and all of those people could not work full-time. It was indicated that the number of staff had increased, but will the witness tell us why that happened and the reason the cost factor seems to have increased? There is obviously an explanation for that.

It appears from the figures presented that costs are way under what they would be if this was a HSE-run facility, so will the witness expand a little on the differences between them, as they could be very relevant? The witness spoke about capital costs for the facilities. Have we any idea, if we were to upgrade the facilities, what the total cost would be? Perhaps we could get an example of one or two facilities, as the costs for all of them are probably not to hand. With regard to long-term planning, do the witnesses see additional increased costs occurring on a year-to-year basis from now on? It was mentioned that costs have risen from €2.4 million to €4.2 million, which is a substantial increase. Is that rate of increase likely to continue or will it level off? The witness indicated that wage costs are only approximately 50% of the overall cost, but in a similar HSE facility wage costs would be approximately 80% of total cost, so could he expand on that as well?

This information would be very useful. The HSE might tell us it is not engaging for reason A, B or C, but that does not seem logical if Camphill is providing a service at a far lower cost base than an equivalent HSE service. Will the witness expand on that so we can have some answers when the HSE responds? It might argue that the cost is too great, which does not seem to be the case. I thank the delegation for the presentation and the work being done by Camphill. All of the people involved are very committed to it, so it is important that it gets the support it requires.

Deputy Mary Mitchell O'Connor: I thank the delegation for its presentation and I am very aware of the organisation, as a friend has been closely involved with the Carlow-Kilkenny Camphill organisation. I also have constituents who are involved with the Camphill in Hollywood, County Down. I thank the organisation for its work, although these may seem like empty words on this side, as empty words will not pay Camphill's bills.

I have examined the numbers supplied by the HSE. Taking the number of residents and dividing it into the €12 million contributed by the public purse, it amounts to approximately €60,000 per person, and that excludes day patients and others from consideration. We incarcerate people in prison, and I hear it costs multiples of that money to keep people in prisons. It goes to show where the focus is in Ireland that people with disabilities and mental health issues are always at the end of the queue. We do our best here. Reference was made to a pilot value for money study. Perhaps the witnesses would comment on the value for money per patient at Camphill versus other agencies. I am aware that there are different types of disability and, therefore, different types of supports required but perhaps the witnesses would outline for the committee how the Camphill Communities of Ireland approaches service provision and the cost per patient in that regard.

Deputy Mary Mitchell O'Connor took the Chair.

Mr. Joe Lynch: I will respond to some of the questions and will then ask my colleagues to respond to others. Working backwards, we were omitted from the value for money study because we were considered an outlier. In terms of statistics, capitation fees in respect of the provision of residential care, which is provided on a 24 hours a day, seven days a week and 52 weeks of the year basis, for 9.4% of our residents is between €20,000 to €30,000 per annum. Capitation fees in respect of 41.9% of residents, which is the largest cohort, are between €30,000 to €40,000 per annum, and for a further 16.7%, fees are between €41,000 to €50,000 per annum. The remainder are above that but they would have serious complex needs. Capitation fees in respect of more than 50% of people within Camphill are less than €40,000 per annum. In terms of the eight agencies reviewed in the context of the value for money study, we would be at the bottom end of the scale compared to all of those agencies.

Acting Chairman (Deputy Mary Mitchell O'Connor): What are the capitation fees for a comparable agency in the public service?

Mr. Joe Lynch: They would be at least double those for Camphill. While needs assessments are carried out in respect of people at the top end of the scale who have very complex needs, such that the correct fees are applied to them, this does not happen in relation to people on the bottom of the scale. Camphill has to hold up its hands in that at the time it was seeking capitation fees, it sought only what it needed at that time rather than what was required in relation to the top end of the scale. Strategically that was a bad move.

Acting Chairman (Deputy Mary Mitchell O'Connor): So, when there was a reduction the agency was hit twice as hard.

Mr. Joe Lynch: Yes. We were hit twice. I will try to put that in context. Capitation fees are paid by the HSE on a monthly basis to each of the communities. On top of that, Camphill receives a top-up payment in recognition by the HSE that Camphill was not properly funded. The top-up fee in 2008 was €2.5 million. In 2009, it was €1.9 million. It then dropped to €900,000 in 2010 and it dropped further in 2011 to €525,000. While other organisations have been hit by cuts of 2%, 3% and 1.5%, Camphill has had its top-up payment reduced from €2.5 million to €500,000 per annum and has also been hit by the 1.5% to 3% cuts across the board, which seriously impacts our ability to provide services going forward.

Deputy Ó Caoláin mentioned the HIQA recommendations. HIQA can order that an agency acquire more staff, upgrade its bannisters, fire services and so on, which must be completed within a specific timeframe. There was a bit of a fudge in this regard between last year and this year. Obviously, people within the HSE must have had the conversation with HIQA in relation to funding for these upgrades, such that fire service upgrades were not deemed an essential part of the registration process. While these services must be upgraded, there was a willingness to allow them to be placed on the back burner because of the amount of money involved. In regard to Deputy Mary Mitchell O'Connor's question in this regard, we need north of €2 million in relation to fire upgrades and so on.

The second recommendation provides that HIQA be permitted to issue an immediate action notice such that agencies will have no choice but to do whatever it says. An agency would generally have 24 to 72 hours to complete the necessary work. Immediate action notices would be served in situations of potential danger to persons. One would have no choice but to find the money to do that work or one could be deregistered or face a fine in court. I will ask Ms Moffitt

to elaborate further on fees within Camphill.

Deputy Jerry Buttimer resumed the Chair.

Ms Miriam Moffitt: My daughter has been in Camphill for the past 16 to 18 years. She is 33 years old and has considerable intellectual disabilities, on top of which she is blind. She receives 24 hour care in Camphill. My totally blind, mentally handicapped daughter receives total care in Camphill at a cost of €33,000 per annum. One would not get bed and breakfast accommodation for that amount.

Chairman: Does Ms Moffitt pay that fee?

Ms Miriam Moffitt: No. The fee is paid by the HSE. The cost of care for my daughter, who has extremely complex physical and intellectual needs, is €33,000 per annum. My daughter is not unique in this regard. In the community she is in, there are 24 people. The fee in respect of 18 of those 24 people is €38,000 per annum or less. There are 15 people in respect of whom the cost of care on an annual basis is €33,000. This cannot continue. It has been maintained up until now through our reserves. Two years ago, we had a nest egg of over €250,000. That is gone. We do not know how we are going to pay wages into the future. Peter and Paul are well robbed at this stage.

Chairman: The HSE in its briefing to the committee said that Camphill has a €4.2 million cash balance.

Ms Miriam Moffitt: In reserves, we have €4.2 million. I have run a business for years. It is good business practice to keep reserves of two to three months. The figure provided by the HSE relates to our reserves. A huge amount of that money has been spent on upgrades ordered by HIQA. The figure which the Chairman has given is no longer relevant in that it has reduced significantly because we have been paying wages out of our reserves. We will not be able to do that for much longer. Camphill is operating on heritage funding. For people like my daughter, whose name is Karen, funding has not been increased. There are people who have been in Camphill for the past 20 to 30 years. People with intellectual disabilities often progress into dementia and Alzheimer's much earlier than mainstream people such that we have people whose needs have increased but in respect of whom funding, because they have been in the facility long-term, is very low. Our people with the highest needs who are longest in the facility are costing a fortune in terms of delivery of care. We are not getting anywhere near the amount of funding required in this regard. At this point in time, we have to consider whether we can offer a safe service and a safe environment for these people. The answer is that we are nearing the end of our capability in that regard.

In regard to whether the sword of Damocles is hanging over us, it is dangling by a very fragile thread. We were able to keep the show on the road but our reserves have been depleted owing to our having to fund wages, upgrade services and meet the increased needs of our residents from those reserves. People with Down's syndrome begin to suffer from dementia as they head into their 50s, which is 20 years earlier than other people. Camphill has been in Ireland approximately 30 years. We have a serious cohort of people who are heading in that direction. It cannot go on.

Mr. John O'Connor: I would like to pick up on a few points. The question on assessments is a very important one because it is one of the things at the heart of the problem. It is also part of the solution to the problem. I was involved in Camphill in Northern Ireland for a number of

years. We had a similar situation in the late 1980s and early 1990s. We dealt with the situation by finding a good robust assessment framework which we rolled out in the communities. An objective figure for individuals was found and their needs were able to be met on foot of those figures. We have been using the supports intensity scale assessment, which was introduced by the HSE in Kilkenny and is an effective assessment framework. It works quite well and can be verified externally by a clinical psychologist. It is a good mechanism for identifying the true costs of an individual's support needs.

There is no perfect assessment framework. Every body or group requires a different type of assessment framework, but this one works well for us. It is recognised nationally and can arrive at a very objective figure for support needs which can be verified. It is an available solution and one that we have been using. We have made some inroads in certain areas using it. In other HSE areas, it has been more difficult to make inroads using it. It is one thing that would be very good as part of the mechanism for addressing these problems. The assessment is there and we are very open to working with the HSE on it.

The other problem we have at the moment is that the face of social care has changed dramatically in the past seven to ten years. We have been working with what we in Camphill call a life-sharing model. We have vocational co-workers. Deputy Ó Caoláin referred to them, as did Deputy O'Connor and Deputy Healy. They have experienced that model through visiting the communities. It has worked very well and has served Camphill across the world, and in Ireland since the early 1970s, very well. However, the model is now changing for a number of reasons. The number of long-term co-workers is decreasing. Every year we have fewer long-term co-workers. When a long-term co-worker is living in a community it means there is not a complete shift system in place. There is an extended family situation in the residential setting. This works very well as there is continuity of relationships and familiarity grows over years. It is the closest thing to a home environment. This is changing because of the change to the face of social care and the pressures placed on the co-worker cohort over recent years. People are being asked to work an extraordinary amount of hours every week, which is not sustainable. People get burnt out. They realise it is not sustainable and that they cannot continue. These issues are eroding the co-worker cohort, which has been at the heart of Camphill. If we could do something in the very short term we would have some chance of addressing some of those issues, but the longer it continues the more people say this is something they cannot sign up to any longer.

Co-workers who are involved in Camphill are involved because they are interested in social care, but they also recognise that there is a richness of life available to those living in a Camphill community. It is a residential setting, but it is a home and not an institution. Anyone who visits a Camphill community recognises quickly that it is based on healthy relationships and recognising the humanity of the people who are living there. A culture develops and this is recognised by families. Families appreciate the culture and individuals who come to Camphill feel recognised and appreciated. Local HSE staff and administrators, social workers and liaison nurses notice the benefits of sending someone to Camphill. It ticks a lot of boxes.

It was mentioned earlier on that two or three of the communities are in serious jeopardy. If something is not done in the short term, we will see serious crisis situations in these communities. They are at crisis point already but they will be in serious crisis situations when the question of closure arises. It would make a huge difference if we could get an assessment mechanism in place and some kind of funding mechanism established that would address short-term issues in under funding. Even hearing that it was in the pipeline would make a huge difference

to morale in the communities.

We welcome HIQA's involvement in Camphill and that of other agencies, and we feel it is a positive thing. There is an increased amount of work and increased costs associated with this involvement but the standard of accommodation in Camphill is well above average. However, we are now required to meet nursing home standards on fire safety in what was a home environment. This sort of thing drives up costs. When a facility is underfunded, items such as maintenance are left on the long finger because we do not want to affect care. Care is the primary concern. We not want to erode the quality of care, so maintenance issues are left unattended. This includes vehicles. It can be sustained for a certain amount of time but after three to five years - this has been going on since 2007 - we get to the point where it becomes unsafe. This is one of the core problems at the heart of the issue.

Mr. Joe Lynch: There are a couple of things that would be good to say for the record. The rates of pay within Camphill are far lower than the industry norm in the community and voluntary sector, particularly in this area.

Chairman: Who sets the pay rate?

Mr. Joe Lynch: We do. We set it ourselves and we advertise it. We do not link ourselves to HSE pay rates or models. For example, on average a personal care assistant will get €14.21 per hour. It is hardly a fortune. It is quite a poor rate, but most of our people would not leave because of the money. They like working in Camphill and with our residents and day attendees. We have stated on the record of the Committee of Public Accounts that nobody in Camphill is on the HSE level 8 salary scale, which is €64,000 a year, or above. We have nobody on €64,000 a year in Camphill. The national governance co-ordinator role and a role such as mine in any other organisation would certainly attract higher pay. I am quite happy to work in Camphill at the rate of pay I am receiving because I love the organisation. It does good work and it is work worth doing. Camphill does not have high rates of pay.

I have an information pack for everyone-----

Chairman: On that point, in his presentation Mr. Lynch said there has been a 9% increase in worker numbers in the past two years. Was approval necessary from the HSE to employ those people?

Mr. Joe Lynch: No. The HSE gives us a packet of money and we have to operate the service within that packet. Unfortunately we are caught between a rock and a hard place. The HSE gives us an amount of money and states that we must operate within that amount but HIQA requires us to have a certain ratio of staff to residents and so on. Therein lies the problem. We need to hire staff because we need to operate a safe service but the HSE says it will not give us any more money. Deputy Mitchell O'Connor asked what the thinking behind that would have been.

Chairman: My apologies, but Deputy Mitchell O'Connor has to speak in the Dáil.

Mr. Joe Lynch: The only thing I can come up with to explain why there has been no engagement with us is that they feel Camphill is a low-cost operation and should be kept that way. We have a very low-cost model and we intend to keep it that way - we do not intend to run away with ourselves. This year alone we have spent €787,000 of our reserve on infrastructural and fire issues within Camphill. The reserve the HSE mentioned as being over €4 million is now certainly below €2 million. That puts us in danger with the charities regulator because the

Charities Regulatory Authority tells us we should have between three months' and six months' running costs in the bank and that would bring the figure up to €6 million. We are caught between a rock and a hard place in that respect.

One of the three communities will run out of cash in the next four to six weeks. We do not have any more money and there is no more money from within Camphill to spread around to all areas. We have already had a cash injection of some €30,000 from central funds but these are down to €88,000 in total so there is no more money to give. The community in question will run into the sand in the next few weeks. We are not sitting on our hands and we have done some fundraising. We applied, using the Camphill banner, for an overdraft facility from the Bank of Ireland and the response from the bank was that it would not approve permanent overdrafts for HSE-funded bodies so there is no money there either. We do not have many options other than to issue protective notices to our staff and ask the HSE to come and collect the 25 people.

Chairman: Have you done that?

Mr. Joe Lynch: We have not done it yet because we were hoping the HSE would engage with us. We had a meeting with the local HSE yesterday morning and it is saying pretty much what the banks are saying. It comes back to Deputy Mitchell O'Connor's point. At local level the HSE says exactly what a bank says, namely, that it is a business case and will have to go to the unit in Dublin. The unit in Dublin then says it cannot give us the money. Therein lies the crux of the matter.

Senator Colm Burke: Mr. Lynch said €33,000 was coming in for individual residents. Is it correct to say the residents are contributing themselves? It is important people do not get the impression they are not contributing. If they get a benefit, then Camphill gets part of that.

Ms Miriam Moffitt: Yes, 50% of the disability allowance, DA, is contributed by the residents, which amounts to €90 per week, which is €4,500 per year. The €33,000 we get from the HSE in my daughter's case is supplemented by another €4,500 from her own DA, which is her property. She holds onto the remainder of the DA for dentists, etc. Effectively, the figure is €37,000 when one puts the two together.

Senator Colm Burke: I have a problem dealing with an estate where a trust is in place for a resident. If there is a trust with a resident in it and the trust wants to provide money to buy, for example, a vehicle, we are now advised that, because other people in the facility get the benefit of that vehicle, Camphill cannot accept the funding. This has arrived on my desk recently and I have raised it with the Minister in the Seanad in connection with the Bill which is being considered there. We need clarification on this point because many organisations such as Camphill have a problem with residents whose parents have died and left funding for them in a trust but the money is left sitting in that trust. Has Ms Moffitt come across this problem?

Ms Miriam Moffitt: I will let Mr. Lynch handle this question.

Mr. Joe Lynch: This concerns a donors' charter, which Camphill Communities of Ireland has. I am not sure whether the trust is bound by legal responsibilities but if a donation is made to a charity for a specific purpose then it has to be used for that purpose. If they donate to buy a vehicle for Camphill Communities of Ireland that is not an issue but if they donate a vehicle for Colm Burke in Camphill Communities, and only Colm Burke can use it, that is ring-fenced. One can, however, make donations and we have received donations from families and friends who have given €50 or €100 to Camphill for any purpose, including paying wages. If it is for

a specific purpose, however, it may only be used for that purpose.

Senator Colm Burke: That is where the problem arises in my case. The funding is in a trust for a particular person but if we give it to an organisation such as Camphill it cannot buy a vehicle for that one person. The family want it to be done but is being told it cannot do it.

Deputy Caoimhghín Ó Caoláin: Did Mr. O'Connor indicate that there was a needs assessment model in place in some areas but not in this jurisdiction? If there is one here, what is its status? He confirmed there was a needs assessment framework in the North. Is it a template we could replicate here? Is it transferable and could it apply here? Would the respective HSE decision makers be familiar with the detail of the approach?

Mr. John O'Connor: The HSE in Kilkenny identified a problem with assessment as regards school leavers approximately ten years ago. It invited a group from America to organise training for a number of senior agency people. They rolled out that training - it is known as "supports intensity scale assessment". It can be linked to value for money and is a very comprehensive assessment framework. We have used it in a number of communities as it gives a very accurate picture of the support scales people need and is an effective way of coming to a figure which can be verified externally if people need it to be, by means of inviting a clinical psychologist to come in and look over the figures. We have done that in a number of situations and the clinical psychologist has often rated the costs higher than the supports intensity scale. It is accurate but we have used it in a way that brings in a realistic fee for people while covering all their support needs. We have recently developed an internal comprehensive assessment tool and we are rolling it out in a number of communities. There are numerous assessment possibilities which could be adopted.

Chairman: How far has Camphill progressed in its engagement with the HSE regarding the remodelling of services?

Mr. Joe Lynch: Our last engagement was in February this year. There was an engagement in August, at which Ms Moffitt was present, on the development of a strategic plan but we have not engaged with the HSE on looking through the model as it has not yet come back to us.

Deputy Catherine Byrne: I apologise for not being here earlier but I was at an earlier meeting. I managed to catch bits of the presentation. I have read the statement and one thing jumped off the page, namely, the life-sharing ethos. I know that means a lot to Camphill and it means a lot to us too. Many groups have taken on the challenges in regard to people with intellectual disabilities, long before the health services have done so. Groups like Camphill Communities of Ireland have been working in every little town here.

Sadly, as the report presented here states, volunteerism is diminishing. While it is not diminishing in every area, the problem is significant in high dependency areas like Camphill's, where people face challenging issues. Also, because of all the rules and regulations that have been introduced for those working with people, volunteers do not find it as easy to volunteer as they did in the past. This probably adds to the decrease in the numbers of volunteers.

I wish to thank Camphill Communities of Ireland. I have visited a number of groups around the country that, like Camphill communities, have a spiritual ethos about them also. This ethos is very much part of how we look at our lives and at individuals who have learning difficulties or mental illness. I thank Camphill communities for what they do in that regard. The Chairman spoke about funding and I will discuss that with him after this meeting. Again, I apologise for

coming late to this meeting, but I was otherwise delayed.

Mr. Joe Lynch: We thank the committee for the opportunity to make this presentation today. The life-sharing model is diminishing a little, but we have quite a lot of short-term volunteers. We do not have a problem getting short-term volunteers, who come from all over the world to assist and befriend people here with special needs. They are fantastic and we could not do our work without them.

Chairman: Sorry, but I wish to allow Deputy Healy contribute.

Deputy Seamus Healy: Mr. Lynch said that one of the Camphill centres is facing closure within three to four weeks. Has the organisation met the HSE on the issue and is it aware of the position?

Mr. Joe Lynch: We met a senior official of the HSE in regard to the local funding yesterday morning. To be honest, we have a fantastic working relationship with most of these people, but the situation was very difficult because, unfortunately, she was looking across the table at me telling me she does not have any more money for us and would have to kick the can up the road to the business unit in Dublin. We have been hearing that same response for many years and the business unit in Dublin seems to be very deaf to anything to do with Camphill and funding arrangements.

Chairman: On that particular point, has Mr. Lynch engaged with the director of services in charge of this area?

Mr. Joe Lynch: That is to be our next telephone call today. Yesterday we engaged at local level because we feel we should not go over the local person's head if that can be avoided. We will engage directly now.

Chairman: My concern is the threat, in terms of the potential closure of the service, which will deprive families like Miriam's. This puts them in a precarious and vulnerable position as they cannot access a service. Is the HSE, at the higher level, aware of the implications of not engaging or of the likelihood that Camphill will not be able to provide a service?

Mr. Joe Lynch: I can only say that yesterday morning when we talked with the senior member in the area, she said she would contact Marion Meany, the second in command to Pat Healy. I can only assume she has done that. At our end, we will do that today, but we wanted to meet with this committee first.

Chairman: Okay. I would like to thank Ms Moffitt, Mr. Lynch, Mr. O'Connor and Ms Finn for being with us today. I am conscious Ms Finn did not get the opportunity to contribute. Does she wish to say anything now?

Ms Anne Finn: No, thank you.

Chairman: I thank all our guests for attending. Following our meeting, we will reflect upon the testimony and will communicate with the HSE immediately outlining the points we have discussed regarding the issues for Camphill.

Deputy Caoimhghín Ó Caoláin: Will the secretariat circulate a copy of our letter to members?

Chairman: Okay. I thank members for their patience. We stand adjourned.

JOINT COMMITTEE ON HEALTH AND CHILDREN

The joint committee adjourned at 1.10 p.m. until 9.30 a.m. on Thursday, 19 November 2015.