

DÁIL ÉIREANN

AN COMHCHOISTE UM NITHE A BHAINNEANN LE MÍCHUMAS

JOINT COMMITTEE ON DISABILITY MATTERS

Déardaoin, 1 Iúil 2021

Thursday, 1 July 2021

Tháinig an Comhchoiste le chéile ag 12.30 p.m.

The Joint Committee met at 12.30 p.m.

Comhaltaí a bhí i láthair / Members present:

Teachtaí Dála / Deputies	Seanadóirí / Senators
Holly Cairns,	Erin McGreehan,
Pauline Tully,	Fiona O'Loughlin,
Violet-Anne Wynne.	Mary Seery Kearney.

Teachta / Deputy Michael Moynihan sa Chathaoir / in the Chair.

Institutionalisation and the Inappropriate Use of Congregated Settings: Discussion

Deputy Pauline Tully took the Chair.

Vice Chairman: Apologies have been received from Deputies Canney and Hourigan and Senators Bacik and Higgins. Deputy Moynihan is unavoidably delayed, but he will join the meeting soon. The purpose of today's meeting is to discuss institutionalisation and the inappropriate use of congregated settings. On behalf of the committee, I extend a warm welcome to our guests: Professor Roy McConkey, Institute of Nursing and Health Research at the University of Ulster; Ms Lynn Fitzpatrick, St. Mary of the Angels Parents and Relatives Association; Professor Gautam Gulati, consultant forensic and general psychiatrist and adjunct associate clinical professor at the University of Limerick; and Ms Ann Marie Flanagan, disability activist.

I remind members that they are only allowed to participate in this meeting if they are physically located on the Leinster House complex or the complex in the convention centre when the Dáil or Seanad is sitting there. In this regard, if members are joining this meeting remotely, I ask them to confirm that they are on the grounds of the Leinster House campus or the convention centre prior to making a contribution to the meeting. For anyone watching the meeting online, witnesses are accessing the meeting remotely. Due to these unprecedented circumstances, I ask everyone to bear with us if technical issues arise.

Before we commence the formal proceedings, I must begin with some formalities regarding matters of privilege. I advise witnesses that they are directed to give only evidence connected with the subject matter of these proceedings. Witnesses are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise nor make charges against any person, persons or entity by name or in such a way as to make him, her or it identifiable. I advise the witnesses giving evidence from a location outside the parliamentary precincts to note the constitutional protections afforded to witnesses attending to give evidence before the committee may not extend to them. No clear guidance can be given on whether or the extent to which the evidence given is covered by absolute privilege of a statutory nature. Persons giving evidence from other jurisdictions should also be mindful of the domestic statutory regime. If witnesses are directed by the committee to cease giving evidence regarding a particular matter, they must respect that direction.

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

I call Professor McConkey to make his opening remarks.

Professor Roy McConkey: I thank the committee for the opportunity to address it. I will focus on people with intellectual disabilities who continue to live in congregated settings, despite the aspirations contained in the HSE report entitled *Time to Move on from Congregated Settings*. I will highlight facts and figures for the committee obtained from our analysis of information contained in the National Intellectual Disability Database. This is managed on behalf of the Department of Health by the Health Research Board, HRB. It is a unique information resource that few other countries have available. Along with colleagues from the HRB led by Dr. Sarah Craig, we have been able to document the gap between policy intentions and the reality. Our findings have been published in international peer-reviewed scientific publications.

In our research, we went back to 2007, when more than 4,000 people with an intellectual

disability in Ireland lived in congregated settings, which are those settings with ten or more residents. We tracked those people from then to 2012, when the HSE's time to move on policy was announced, and on to 2017 to see what changes, if any, had happened over those ten years. Although there had been a 30% reduction in numbers by 2017, the latest date for which we have information, more than 3,000 people remained in such settings. However, this reduction was more marked in certain community healthcare organisation, CHO, areas than others, and reductions had begun in some areas even before the time to move on policy was announced. Some of the reduction was due to deaths, but over these ten years approximately 750 people had been resettled from congregated accommodation. Therefore, the policy was feasible, albeit only small numbers of people were able to avail of it.

Here is the rub, though. Almost the same number of people had been admitted to these settings over those ten years. Why? Largely, it was because the policy of no new admissions contained in the policy document had not been followed. If a crisis arose and no alternative provision was available, then people had to be admitted somewhere and that happened to be into congregated settings. The fact that people continued to be admitted to these settings prolongs the time that people continue to use congregated settings.

Our analysis went on to identify the people at the greatest risk of living in congregated settings. They were people aged 55 years and over, those with more severe disabilities and those living in accommodation provided directly by the HSE rather than by voluntary organisations. We drew four lessons from this analysis. First, policy implementation occurs unequally, even in a country as small as Ireland. Who allows this to happen? Second, certain areas are more receptive to innovation than others. We need to understand the reasons for this, although I suspect that local leadership is likely to be a leading factor. Therefore, have we invested in changing the hearts and minds of service providers and professionals who have direct influence over the type of services that we provide? Third, if the 30% reduction of people living in congregated settings took ten years to achieve, and if the process is not accelerated, then it will be a further 20 years, until 2040, before congregated care in Ireland is confined to history. Can we afford to wait that long? Fourth, so-called "bed reduction", or removing people from congregated settings entirely, cannot occur in isolation from creating alternative and better provision.

Other studies we have conducted in Ireland have demonstrated that improvements in people's quality of life come from person-centred and community-based supported accommodation. This is where future investment needs to be made, if the State is to maximise the value for money it obtains from intellectual disability services. I hardly need to remind the committee of the similarly entitled report, Value for Money and Policy Review of Disability Services in Ireland, that was issued by the Department of Health in 2012. It was published nearly ten years ago. Why, then, does it take so long for things to change for people with a disability in Ireland? Hopefully, that is a question that the committee will ponder.

Vice Chairman: I thank Professor McConkey for that opening statement. I now call Ms Lynn Fitzpatrick to make her opening remarks.

Ms Lynn Fitzpatrick: I thank the committee for the opportunity to give voice to my brother Bernard, who cannot represent himself due to the profound nature of his disability. His 40 years of lived experience in residential care is a crucial consideration for today's discussion, but not for the reasons one might assume, given that Bernard has never lived in an institution or inappropriate setting. He has lived in St. Mary of the Angels.

Bernard lives a full, valued and meaningful life on a tranquil 30 acre campus in Beaufort not

far from our family home in Cahirsiveen. When we were kids, Bubo, as we have always known him, spent weekends, holidays and special occasions with us. During the week, he lived among his peers, who at the time were children with severe or profound physical and intellectual disabilities. My mom recalled the impact on Bubo after he moved to St. Mary of the Angels at five years of age:

Everything in his world changed for the better. His epileptic fits began to diminish.... The immense heartbreak I [initially] felt ... was soon replaced with ... gratefulness that my son was in the best place, getting the best chance for a long and healthy life.

Bubo and his friends grew up together in an environment that was purposely built for them. From its founding in 1968, the campus was developed and upgraded with them specifically in mind. The on-site facilities include a heated hydrotherapy pool, a sensory room with heated water bed, a wheelchair swing, outdoor sensory equipment, occupational therapy, physiotherapy, music therapy, jacuzzi baths, psychology, psychiatry, massage, speech and language therapy, dentistry, GP visits and a day centre for crafts and cookery. There is also a special school and a chapel that many individuals can walk or cycle to independently. Recently, the local community raised €500,000, which was used in part to improve walkways and landscaping and to construct new bedrooms and sunrooms. Today, Bubo is at home on holidays, but if he was in Beaufort, he would probably be at a tea party with friends or spending time in the spectacular grounds. He might be planting flowers in a sensory box on the patio outside his private en suite bedroom or chilling out in the hydropool. Maybe he would not be there at all and instead be out on one of his regular day trips to the nearby towns of Killorglin or Killarney, all this with the help of the exceptional front-line staff who know him so well.

This is Bernard's life now, but his future is uncertain due to Government policy. The 2011 Time to Move on from Congregated Settings report identified St. Mary of the Angels as one of 72 residential settings to close within seven years purely because it was campus-based. If Bubo could tell us where he wanted to live, we believe he would choose his current place of residence, but this policy mandates that he move out to live in its preferred place of residence, that is, in "ordinary neighbourhoods", and sets out narrow parameters within which Bubo can make choices. In this way, the policy denies people such as Bubo rights afforded to them under Article 19 of the UN convention.

The policy also ensures that people such as Bubo will be forced to comply by issuing a further mandate, namely, that there be no new admissions to congregated settings. With an ageing population, it is inevitable that the number of people living in St. Mary of the Angels will dwindle, making it economically unviable to maintain its facilities. Ultimately, numbers will fall to an extent that makes it impossible to stay open for the few who remain. Meanwhile, Bubo's vibrant community will diminish and he will notice a change in his environment. It will feel lonely and isolated. His home could become an institution for the first time.

The policy removes Bubo's right to live on a campus and denies this right to all current and future "Bubos" because its implicit aim is to eliminate congregated settings and its explicit aim is that there be "no further need for congregated settings". This, too, violates a right under the convention to make choices on an equal basis with others, since campus living is an option open to other cohorts of society such as students, older people and even some people with disabilities.

The policy insists that Bubo will not live in a community until he is in an "ordinary" place being an "ordinary" person, but a community is, by definition, "a group of people living in the same place or having a particular characteristic in common". Bubo lives among people with

whom he shares much in common. The Government should not define “community” for the individual. Rather, it is the individual who should define the communities in which he or she wishes to participate. For Bubo, moving to “the community” means losing lifelong friends and having nothing in common with his new neighbours.

Research supporting the ideology that ordinary community living is best for all people with disabilities “no matter how severe or complex” must take into account the unique needs and real lives of the minority - 14% of people with severe intellectual disabilities and 4% with profound intellectual disabilities - for whom a dramatic change of setting and routine could have negative consequences. The essential facilities they need will not be available to them out there in the community any more than they are available now to the families with disabled children who are crying out for such facilities.

Decongregation has played out internationally with tragic consequences. To date in Ireland, the only stories getting airtime are the successful ones. I cannot ask the committee to take my word for it that, so far, this policy has badly failed some vulnerable people, but please consider the fact that, since its launch, 278 people were admitted or readmitted into congregated settings in the period 2012 to 2019. This happened despite the policy’s aim to remove the need for such places. Where are these people supposed to go when the door to the last “St. Mary of the Angels” has shut for good?

I put it to the committee that St. Mary of the Angels is a community in its own right with a proven track record of success spanning six decades. It is a residential care model that should be researched and replicated, not broken up and sold to fund community living. In closing, I ask the committee to support my request that St. Mary of the Angels be immediately exempted from the Time to Move on from Congregated Settings policy, which should never have targeted it in the first place, let alone designated it a pilot and priority site for decongregation.

Vice Chairman: I thank Ms Fitzpatrick for her opening statement. I call Professor Gulati to make his opening remarks.

Professor Guatam Gulati: I thank the committee for the invitation to attend this meeting. My evidence will relate to my individual viewpoint as a clinical academic and does not represent the views of the HSE or any other affiliation.

The Irish ratification of the UN Convention on the Rights of Persons with Disabilities, UNCRPD, in 2018 enshrined the rights of people with disabilities in an international convention, providing much-needed momentum to reform of this area. This is particularly the case for people with psychosocial disabilities and people with intellectual disabilities. Article 19 recognises the equal right of all persons with disabilities to live in the community with choices equal to others. The report of the HSE working group on congregated settings in 2011 made a compelling case for urgent action in this respect.

Data from the implementation group recorded a 30% reduction in the number of residents in congregated settings between 2012 and 2017. However, a report in 2018 by Inclusion Ireland raised concerns about limitations in the scope of policy and rate of progress in deinstitutionalisation. The report raised the issue of people with disabilities moving between institutions, stating:

For example ... in 2015, less than 10% moved into their own home. Almost three quarters of those who moved actually moved to other institutions.

Against this backdrop, I intend to share a specific viewpoint with the committee relating to people with psychosocial and intellectual disabilities and the intersection of Articles 13, 28, 11 and 19 of the UNCRPD in respect of a process referred to as trans-institutionalisation. Trans-institutionalisation refers to a process whereby individuals who community care policies intended to deinstitutionalise in practice ended up in different institutions rather than their own homes.

I will briefly speak about people in prisons, people who are homeless and people who are seeking asylum. In terms of people in prisons, against a backdrop of the closure of a substantial number of psychiatric beds, a study that evaluated publicly available Irish data from 1986 to 2010 found an inverse relationship between psychiatric admissions and prison committals. More specifically, this study found an increase of 91 prison committals for every 100 psychiatric hospital admissions foregone. There is a lack of up-to-date Irish data in respect of people with psychosocial disabilities in the criminal justice system. However, the available data suggests that approximately one in three prisoners screen positive for intellectual disabilities, one in two for substance misuse and dependence and that the prevalence of severe mental illness in Irish prisons is four times that of the general population. This is borne out in clinical practice where it is not unusual to come across individuals with multiple disabilities, including intellectual and psychosocial disabilities, in a prison setting. It is also possible to trace a link to a paucity of community supports prior to incarceration. Furthermore, the provision of equivalent care for these individuals as set out in the Nelson Mandela rules is challenging, with systemic and legal barriers to diversion in Ireland. It is important to ensure that Irish prisons are not, in effect, emerging as congregated settings for people with psychosocial and intellectual disabilities.

In regard to people who are homeless, a recent study in Dublin funded by the National Disability Authority, NDA, in respect of people with intellectual and developmental disabilities found 145 individuals or families identified as homeless or at risk of homelessness. This represents one study from one region in Ireland. An Inclusion Ireland report, using 2016 census statistics, found that people with an intellectual disability represent 1.4% of the total population and 3.1% of the homeless population. The link with homelessness extends to people with psychosocial disabilities. A recent study in acute psychiatric inpatient units in one Irish region found that approximately one in three inpatients were homeless or had a history of homelessness. More than one in six people committed to Irish prisons are homeless at the time of committal and there is a link between disability, incarceration and homelessness. A 2012 Irish study found a high prevalence of psychosocial disabilities among people in a Dublin hostel for homeless people. Article 28 of the UNCRPD places a duty on the state to ensure equal access by persons with disabilities to public housing programmes. We need to ensure that hostels for people who are homeless are not, in effect, emerging as congregated settings for people with psychosocial and intellectual disabilities.

On people seeking asylum in Ireland, there are more than 7,000 people living in direct provision in Ireland, 30% of whom are children, with an average stay of 24 months.

A study in direct provision centres in Sligo and Leitrim found that asylum seekers were six times more likely than refugees to report symptoms of post-traumatic stress disorder, PTSD, depression or anxiety. A study in a Galway primary care setting found that asylum seekers were five times more likely than Irish citizens to be diagnosed with psychiatric illness. Little is known about the prevalence of people with intellectual disabilities in the direct provision system. However, there is international recognition of the additional barriers people with intellectual disabilities face in the asylum process. Article 11 of the UNCRPD requires the state to take all necessary measures to ensure the protection and safety of persons with disabilities

in situations of risk, including situations of armed conflict and humanitarian emergencies. We need to ensure that direct provision centres do not emerge as congregated settings for people with psychosocial disabilities.

Further to the McMahon report, the Government White Paper on ending direct provision is to be welcomed both in reference to housing and community inclusion. It would be important that people with intellectual and psychosocial disabilities are appropriately supported through this process to avoid a risk of trans-institutionalisation. Decongregation of people with disabilities from institutions can be positive. However, it must be accompanied with community supports and inclusion strategies to avoid a risk of trans-institutionalisation. The right of all persons with disabilities to live in the community, with choices equal to others and with full inclusion and participation is a basic right. Realising this in practice is a litmus test of our commitment as a society to the values of the UNCRPD. I thank the committee.

Chairman: I thank Professor Gulati and I invite Ms Flanagan to make her opening statement.

Ms Ann Marie Flanagan: I thank the Chairperson and members of the joint committee for the invitation to contribute today. I want to dedicate this contribution to Jennifer Hynes who, as some of you will know, is a stalwart, amazing self-advocate who has found herself in a nursing home since 2019, and to the Clare Leader Forum, a pan disabled people's organisation, DPO, which believes in the right to live a life with dignity, privacy, equality, respect and autonomy, driven by the mottos, "rights not charity" and "nothing about us without us".

Article 19 of the UNCRPD, coupled with the commitment of the Oireachtas, are central to realising our human rights. For so many in society a place to call home is one of the most pertinent issues of our times, but it is impacting disabled people, women, men and children of all ages and impairments, disproportionately. This is a welcome opportunity to contribute to a narrative of human rights of disabled people with regards to a home, independent living and community participation. We need a paradigm shift in realising disabled people as rights holders. Prevailing attitudes and practices interfere with disabled people being recognised as needing their own homes to live, participate and work in our communities as per our will and preference equal to others.

Disability injustice and ableism are among the key drivers for continued investment in practises that sustain the deprivation of liberty, inequity in accessing justice and the lack of supports for independent living. Homelessness is hidden by policies of institutionalisation in residential centres, nursing homes, hostels and relatives' homes. Disabled people often have no choice but to live with relatives owing to the lack of independent living supports and housing. My contribution to the discourse on the right to independent living is to evoke an urgency to act swiftly, intentionally and empathically to redress these inequalities and to meaningfully include us - disabled people - in the solutions.

Personal assistant services, PAS, and a home are fundamental human rights, as per Article 19. The exclusion of a significant portion of the population from statistics and policy responses to homelessness, housing needs, unemployment, etc., further normalises the othering and segregation of disabled people. For example, clumping PAS hours with home help and home care, without a right of the disabled person to a minimum number of hours to support him or her, has similar consequences. Disabled people become institutionalised in their own home, consequently. Disabled people include people with long-term physical, mental, intellectual and sensory impairments which in interaction with various barriers hinder full and effective partici-

pation in society equal to others. Disabled men, women and children have a need for a home that is equal to that of non-disabled people. Disabled people are not vulnerable by virtue of impairment, but as a consequence of the medical model, oppressive and, at times, harmful systems. There are overwhelming systemic policies and services that segregate, maintain inequality and fuel ableism as a normative and acceptable response to disabled people. These need to change. They limit the meaning of a home, community participation, private and family life.

The majority of society understands disability through a non-disabled lens, which reduces the rights of disabled people. Disabled people are disproportionately impacted by deprivation, including homelessness. Systemic ableism assigns value to appearance, ability to reproduce, earn, and ascribed behaviours, evaluating a prescribed inability to conform to a constructed idea of normality, intelligence and productivity. The terms “homelessness” and “a home” when describing disabled people’s living situations are not generally ascribed. It is assumed that disabled people either remain in their family homes with ageing relatives or live in institutions in the form of residential care, nursing homes or hostels. It is normalised to such a degree that many family members also believe that institutions are where disabled relatives need to live for their own safety.

The report, *Wasted Lives: Time for a better future for younger people in nursing homes*, made for difficult reading. I thank Mr. Peter Tyndall for giving a voice to the 1,300 young people who are in nursing homes for older people through no fault of their own other than having an impairment that requires independent living supports and a lack of recognition of their right to autonomy, privacy and dignity in their own homes. It was harrowing to read about how there was for too many a lack of informed consent and a belief that it would only be for a short while, turning days and weeks into years. To learn that four people have died since the publication, 20 more people have entered nursing homes and only 18 people are due to be supported in leaving is devastating for me, the Clare Leader Forum and the movement.

There remain 3,000 people living in congregated settings, which means ten or more other people living in one space. Fundamentally, it means that they have no tenancies, no control and no decision over who is recruited to provide them with assistance. Most people do not decide to be segregated from their communities and families. The evidence shows that they are at greater risk of having a poor quality of life compared to people living in the community. They continue to live in unsuitable, outdated accommodation. Important aspects of everyday life are unavailable in most cases, for example, private homes, access to their own kitchens where they get to cook with assistance or access to laundry facilities.

We have no statistics on the number of people who are forced to live with elderly parents or relatives due to the lack of vital supports that provide independent living opportunities. It is assumed that adults with disabilities choose to live at home for life, but many do not. It keeps people in poverty traps, forcing disabled people to resort to relatives becoming “carers” and themselves becoming passive dependants, oppressed and depressed.

We must re-examine the €2 billion spent on specialised services through the lens of disabled people’s human rights. We need to question the assumptions that residential care, years in day services with little to no progression, residential respite services, the lack of transport and being segregated from community life for all their lives are what disabled people want and need. We need to move beyond traditional service-led models that perpetuate paternalism and believe that disabled people are less entitled to independent living, a home and a family life.

The consequences of systemic and cultural ableism exclude disabled people from main-

stream news reports, political debates and conversations about housing and homelessness. For example, when we hear about homelessness, it does not conjure up images of disabled parents, disabled children or disabled rough sleepers. The data show us that one in four homeless people on the social housing waiting lists are disabled.

I wish to share with the committee some examples of disabled people's lives, the first of which is that of a mother with MS whose leg is so heavy that she cannot lift it anymore and whose arms are weak, making it difficult to use her crutches. She has four children between aged between three years and 12. She is living in emergency accommodation. Her children attend school three miles away. Their living situation is unbearable. Her pain and fatigue make it more difficult and her stress is exacerbating her impairment. Her need for a home is urgent. Her key worker talks about finding a homeless hub, but that is not a home, and it certainly will not meet her physical support needs.

Another example is that of the parents of three children, one of whom has a physical disability, who are looking for emergency accommodation. The landlord sold their home. The father had to reduce his hours and the mother had to give up her job. Can the committee members imagine their poverty? Their child's access needs and the lack of accessible housing, or housing at all, keeps them in emergency accommodation.

Another example is that of the disabled mother in a domestic violence situation, scared for her children and herself. She cannot leave because she does not have personal assistance hours. Her abuser is the person assisting them. Shelters cannot accommodate her access needs or her hoist and do not have the resources to provide personal assistance. There is no end in sight for her.

What about the university graduate who qualified with a masters? She was offered a permanent job but had to refuse it because her personal assistance hours and her supports from the Department of Education were taken away while she was a student. She moved down home to live with her sister and is sharing a room with her young niece. As a result, she lives in abject poverty and is forced to live on disability allowance. She has sunk into depression. Just to get out of the house, she goes to a day centre.

Another example is that of the 39-year-old woman who had to leave her home. She had a physical impairment and a local authority house. She went to hospital, but it did not have enough personal assistant support hours for her. In April 2019, she agreed to go into a nursing home temporarily. She is still waiting there. Like the other 1,300, she spent the past year and a half locked in a room because of Covid-19. Now that she is finally out of the room, she patiently repeats the same conversations day in and day out with many of the other residents, who are at the end of their lives with advanced dementia. Her life is ebbing away. She is becoming institutionalised and does not believe that she will ever get out.

Another example is that of the 27-year-old woman who arrived at a homeless clinic mid-pandemic in rural Ireland just a few months ago with her bags in her hands and looking for emergency accommodation. She was known to them, but she was refused that support and was told to go home to her father. She could not. She tried to explain why and was emotional. As a consequence, her mental health deteriorated. She ended up being admitted involuntarily by the Garda. This devastated her and she became hopeless. Due to the condition of her mental health, which was a consequence of being rejected and not listened to, she was eventually given temporary accommodation. However, it is temporary and she remains fearful, which is impacting her mental health recovery.

Another example is that of the 30-year-old woman with an intellectual disability who excitedly moved into what she thought was community living only to find herself living with two other people with whom she had not chosen to live. She was promised independent living, choice and control in her life, but because that organisation only has funding for one staff member every day, she finds herself walking along the streets and going to events in groups. That is a form of institutionalisation. She did not want that and did not know it was what she was accepting. Due to her having an intellectual disability, she is not allowed to do things independently. She is depressed and is not being listened to. Where are her will and preference?

Disabled people need to be recognised as having social, economic and cultural rights with the necessary infrastructure and supports. Disabled people need to be heard. People who are categorised as having complex needs, those with intellectual disabilities, people with significant mental health issues and people with high physical and sensory support needs deserve to be supported to live their chosen lives, not equal to other disabled people, but to other human beings. As we have stated time and again at this meeting, Article 19 of the convention states that, equal to others, disabled people have the right to live with whom we want and where we want and to have the supports that meet our unique needs. This article does not select people depending on our impairment or perceived capacity. It means everybody.

It has long been accepted in Ireland and internationally, and is now covered by Article 19, that personal assistant support services offer disabled people independent living, yet after 30 years, it accounts for less than 5% of the €2 billion budget. This matter needs to be examined. Personal assistant support services are only offered to people with physical and sensory impairments whose functional needs require support. People who need support in making decisions continue to be victims - that is the word we use - of wardship under the Lunacy Regulation (Ireland) Act 1871. It must be repealed urgently. We ask the members of the committee to work with their colleagues in the Oireachtas to commence the Assisted Decision-Making (Capacity) Act 2015 fully and on time, as promised. These outdated laws and policies feed an ideology that holds that people with significant impairments are subhuman and a drain on finite resources. These policies and practises maintain structural and systemic institutionalisation of disabled people.

It is not all about resources. To make sustainable, meaningful change, the State must support true and meaningful involvement by all those directly impacted. There are many ways to do this. People with a disability who are critical thinkers and solution-focused could be sought out. Capacity could be enhanced for other disabled people, as is necessary. People with different impairments and cultural backgrounds could be included. Disabled people should be viewed as having the same value as expensive external consultants. We are the experts. We have the solutions. We can support the State to support us. I hope fundamental human rights will be the driver for continuing work in this area and that there will be sustained dialogue with and meaningful inclusion of disabled people at all levels in respect of policy, law reform, finance and system change.

Vice Chairman: I thank Ms Flanagan for her opening statement. Following the speaking rota for members, I call Deputy Cairns.

Deputy Holly Cairns: I thank all the witnesses for appearing before the committee. The dignity and rights of those individuals affected is at the heart of this subject for me and for this committee. Our systems still have a kind of paternalistic attitude that views people with intellectual disabilities as requiring care, rather than enabling them to live as independently as possible and appropriate. Choices in this regard are limited to congregated settings, which we are

trying to move away from, or dependency on family care, which presents its own challenges in respect of an ageing population and the disgraceful way in which carers are treated. We must replace this system with a one-size-fits-all model that focuses on one thing, which is individual rights.

The slow progress made in the HSE's time to move on policy in respect of congregated settings is symptomatic of this perspective. Since the strategy commenced, of the initial 4,000 people identified, only 661 people have been supported to transition out of congregated settings. As Professor McConkey said, at this rate it will be another 20 years before decongregation is completed. We must also be aware that this issue concerns people with intellectual disabilities whose rights to act on their own behalf are legally limited, especially given the delay in the commencement of the Assisted Decision-Making (Capacity) Act.

My first questions are directed to Ms Flanagan and Professor McConkey. Ms Flanagan highlighted the importance of the personal assistance service, which offers disabled people independent living. I ask her to elaborate on what we must do regarding policy and legislation to ensure that a system based on personal assistance is in place for all disabled people. Turning to Professor McConkey, I ask him to outline the significance of an individual resource allocation model, in which budgets and supports are assigned to individuals based on need. I refer to the potential of such a model to enable disabled people to employ personal assistants and to secure the specific support services they need, especially with respect to engagement with the community.

If there is time then, perhaps at the end, I have a question for Professor Gulati. He spoke about the disproportionate number of people with intellectual disabilities living in emergency accommodation. The historical absence of independent, supported living accommodation and, as far as we know, in our new builds as well, is probably the biggest contributor to this. Will he please comment on whether other systemic barriers or factors contribute to this disproportionate number of people with intellectual disabilities residing in emergency accommodation?

Deputy Michael Moynihan took the chair

Ms Ann Marie Flanagan: I thank the Deputy for the question. Ireland is unique compared with most European countries in that we do not have legislation that provides a legal entitlement for disabled people to have services in their own right. My direct professional experience includes working in the United Kingdom under community care legislation where direct payments were enacted in 1996. Nothing is perfect, but that approach certainly does provide a right in this regard to disabled people of all impairments. This is another problem in Ireland. We silo disabled people based on our impairments. That then perpetuates the idea that people with intellectual disabilities and other impairments do not have the same drive for independent living as people with other impairments, such as myself.

The situation then becomes based on economic value. Therefore, someone like me who has personal assistant support can get work and contribute financially. However, we do not know the overall value in respect of an individual's life or the economy, because we have never organised ourselves in a way that provides independent living supports to disabled people. Therefore, first, personal assistant support services must be legislated for and provided to all disabled people. This is another example of the need to reorganise independent living supports. Ireland, for example, has the third highest rate of unemployment and poverty for people with disabilities in Europe, next to countries in eastern Europe. That statistic comes from a report carried out by the European Disability Forum last year. It is a shocking statistic. One of the

wealthiest countries in Europe has one of the highest rates of deprivation and poverty among disabled people. This is related to how we organise services and supports for disabled people.

In addition, and this is not a criticism of the sector, but the relationship between the voluntary sector and the State excludes disabled people. This goes right back to the 1950s and, indeed, to the foundation of the State. In 1984, approximately 140 organisations were providing services to people with intellectual disabilities. Therefore, there is no space for disabled people to speak up for ourselves, to represent ourselves and to say that we want the funding to manage our own lives. Equally, the lack of progress being made in providing autonomous independent support for people with capacity “issues” to represent themselves is also problematic. Like Deputy Cairns, I also call for the commencement of the Assisted Decision-Making (Capacity) Act. We must legislate for personal assistant supports. It must also be understood as well that this does not involve just one thing. We must build supports to ensure individuals can have choice and control in their lives.

Chairman: I thank Ms Flanagan.

Deputy Holly Cairns: I just remind the Chair that I posed three questions to the witnesses in total.

Chairman: That is fine. I call Professor McConkey to respond first.

Professor Roy McConkey: The Deputy made an important point regarding how funding is delivered to people with disabilities. We rely a great deal on what is called block funding. For people in congregated settings, for example, the service provider will get an amount that is then averaged out among 20, 30 or up to 50 people. Therefore, the averaging out of the funding means that people with high needs are underpaid, while those people with low needs are overpaid. Many economists will recognise this situation as an inefficient way of doing this. The solution, therefore, is to try to do an assessment of people’s needs to allow for direct resource allocation to meet the particular needs of each person. Those could be personal care needs, social inclusion needs, etc..

Many jurisdictions have moved to exploring options for individualised funding being made available. However, many service providers would see this as being a big threat to the maintenance of their existing systems. Those systems have been set up with the assumption that providers will get a year-on-year increase on whatever amounts they have received historically, which those organisations would argue provides for better planning. Of course, what is being done in that current model of funding is perpetuating a model of service that we may wish to get away from. Some of the innovative providers are starting to explore how they could create services in which individual allocations are all added together to provide the outcome of the moneys that are needed to sustain that service. There are examples around Ireland where this is happening.

There is a need to look at value for money in regard to whether we are overpaying for some people who are getting more care than they need, or underpaying for those people who need much greater care. Mention was made of nursing homes, which is a big problem in the North of Ireland as well. The danger is that people are placed into nursing home care who could live in a community setting, with support from personal assistants, at a much cheaper cost than what is being paid for nursing home care. However, it is convenient for the bureaucracy to keep putting people into those sorts of settings rather than having to redesign services that are more responsive to people’s needs. That is the challenge that Ireland needs to take on board, along

with other countries as it is not unique to Ireland.

Deputy Holly Cairns: My next question is for Professor Gulati, who spoke about the disproportionate number of people with intellectual disabilities in emergency homeless accommodation. I presume much of that is to do with the fact we do not have enough builds for independent supported living. Can Professor Gulati give us any insights into what other structural and bureaucratic barriers there are in that regard?

Professor Guatam Gulati: That is a very important point. In my experience, the biggest barrier to getting the right supports is that the disability might not be recognised at all. I do not think that, sitting here today, we even know the extent of the number of people with disabilities who are present in homeless hostels around the country. A lot of disability goes unrecognised and, without recognising it, we cannot offer the right supports.

My second viewpoint, again from my clinical experience, is that it is unusual for people with disabilities just to have the one disadvantage, and if they have one disability, it is more than likely they have another disability. For example, it would not be unusual in my practice to see people with psychosocial and intellectual disabilities who have lived a life of poverty and who may be homeless, and stigma remains a real issue for them even now in 2021.

Deputy Violet-Anne Wynne: I thank all the speakers, who offer diverse expert voices through advocacy, academia and direct lived experience. Each of them brings an expertise on the issues of institutionalisation. It is an important topic that we are discussing. Deinstitutionalisation has been on the political agenda for at least three successive Governments, following the HSE's Time to Move On From Congregated Settings report from 2011 and, on the other hand, the fact we have a strong social and historical culture of institutionalisation.

Last week, we met with the Ombudsman, Peter Tyndall, who was discussing his Wasted Lives report. One of the most striking conclusions drawn in his report was that even young people in these nursing homes still did not have access to appropriate or satisfactory primary health and social care support. The fact that disabled people need additional supports is often used as a justification for their accommodation in institutional settings, usually at the cost of their rights, such as the right to privacy and family life. If their support needs are not being provided for, then it is a lose-lose situation in which their rights are being dismissed and are not being met.

My first question is to Ms Ann Marie Flanagan and I would like to come back in when she has responded because I have two further questions. How can we have more meaningful engagement with disabled people under Article 4 of the convention, which requires state parties to consult meaningfully with people who carry the voice of direct lived experience? As a committee, how do we engage less with service providers and more with DPOs? I am grateful that I have regular contact with the Clare Leader Forum, my local DPO, which flags rights-based issues and keeps me up to speed on the voice of direct lived experience that is so often missing from these discussions at national level. How do we rectify this and honour the ethos of "nothing about us without us"?

Second, and on a related note, Ms Flanagan might talk to us about the importance of disabled people leading the conversation on how the State can ensure it meets its full obligation under Article 19 and the rest of the convention, and the value, ethically, morally and socially, of a genuine inclusion of disabled people in decision-making processes.

As a lead activist in the cause for legislating for PAS and after the motion was passed unanimously in the Dáil, what has the feeling been like in the movement since there has been no progress or movement towards putting such services on a statutory footing?

Ms Ann Marie Flanagan: I thank the Deputy. I will try to remember all of those questions. The first thing to remember is that, in Ireland, we do not have a funded and recognised statutory engagement process with disabled people. Again, we need to acknowledge the political and cultural norms that exist and the fact the State goes to very organised service providers. That is a particular lens and it is there, whether disabled people agree with it. However, at a minimum, there has to be equal investment in giving voice to disabled people.

I want to take the opportunity to explain the power of DPOs. At local level, we have the collective of disabled people across impairments, lived experience and understanding of self-worth. As a consequence of coming together and the peer support that is fundamental, I have watched the empowerment and the voice of individuals. Until now, the majority of people have been living at home with families, they access day services and they are long-term unemployed. They would not have seen themselves as equals and, because they were not deeply unhappy, they believed this would be their best lot and they regularly used reductionist language in describing themselves. What I want to express, and this is important, is that disabled people, because they do not have supports, are dependent on the love and goodwill of brothers, sisters and elderly parents in the main. They are uncomfortable with challenging that because of the level of gratitude and love they have. However, so many people have shared with me that they feel guilt, they do not ask for what they want and they fit in with what the family does. Many people would say that at the age of 25, 30 or 35, they feel like their little nieces and nephews and, as somebody said to me recently, they fit in with what the children do in the family. That has nothing to do with their impairment. It is to do with how they are treated and viewed within the family dynamic, because the family dynamic is that they are members of the general population, and the general population still seems to see disabled people in a paternalistic way.

I am in my mid-40s, I have a career, I am a mental health professional, I have PAS and I have a child, yet I experience ableism every day of the week. For example, I could be at a meeting with other mental health professionals who do not have disabilities. I might have made a contribution on a recovery solution for people we work with and it would be unheard. I know myself that, as a consequence of ableism, it is heard differently by somebody else. I am the lived experience. I feel it every day. Another example is around the need to have protection and the right to PAS. HSE organisations are running out of money because there is no national legislation that protects the hours and gives a standard of support for disabled people. Regularly, CHOs make cost-cutting decisions, regardless of risk assessment or impact on disabled people. The other thing in engaging with HSE organisations regularly, they say they are crisis managing. It is never about the quality of life. We now know the personal assistant services has become a form of institutionalising people. It is called personal assistance because it comes under a budget, but it is home help. The average time that people get per day is one hour and, therefore, people are not planned for.

A HSE representative mentioned an assessment at a recent committee meeting, although I cannot remember its exact name, that is being used for people in nursing homes and other congregate settings. However, it is a deficit model. It looks at disability and what people cannot do. There are no recognised assessments that engage with disabled people and ask them what they want for their lives and offer them all the supports they need. The State maintains that it should meet the minimum needs of individuals.

I also wanted to give another example of how funding is spent and the cultural norms around that. For example, when we look at the employment policy for disabled people, again, much of the funding is about compensating employers. We are almost selling the idea that employers are doing this disabled person a favour by employing them; that it is almost charity and a social service, rather than employing people. Rather than providing supports for the individual to do the job equal to others, we are compensating employers through grants. We are convincing people that they should do the right thing. Of course, everybody has social responsibilities, but when there is an imbalance between the right of the potential employee and the compensation of prospective employers, this feeds into the idea of inequality and that disabled people are less equal. There is a need to legislate for personal assistants for everybody. I have said that previously.

The Deputy asked about the mood. I recall in November 2019, the excitement when a unanimous motion passed. It was 7.30 p.m. There were many people either in the Gallery or watching from home. Deputies spoke passionately about disabled people and activists whom they knew at local level and they were supportive of the establishment of a commissioner to look at what is required. Yet, it is not even in the programme for Government. It is exhausting for disabled people. The committee has heard the evidence from everybody time and time again. We are the poorest and we have the fewest services, yet we do our best to be as vocal as we can to ask for our rights to be protected.

Ireland was the last country to ratify the UNCRPD. I ask on behalf of disabled people to please not implement this in a minimalistic way, but to embrace all the articles in the convention, see us as equal to yourselves as citizens and constituents and support the realisation of our rights. That can only be done by interrogating the existing way that services are provided and by looking at the individual and seeing their potential, rather than seeing their minimum needs within a traditional medical model approach to providing disability services. I hope that answers the Deputy's questions.

Chairman: Would Deputy Wynne like to pose another question or two?

Deputy Violet-Anne Wynne: I thank Ms Flanagan for her responses and for all the good work she does through the Clare Leader Forum.

My next questions are to Professor McConkey. Based on his comments on the Time to Move on from Congregated Settings report, the failure to implement a no new admissions policy has meant that there has been an almost one-in-one-out door policy with numbers of admissions, vastly minimising the efficacy of transferring people out of congregated settings. As he noted, it will take another two decades to eliminate congregated settings if this pace is maintained. Are we equipped to implement and no new admissions policy? What would that look like? The focus has been on transfers out of these settings, but we need to redirect some attention to preventing people from involuntarily becoming accommodated through congregated care.

Professor Gulati made reference to trans-institutionalisation, which is a valid point. Ireland has an historic tendency towards this. How does he envision preventing this, even if some disabled people who, through will and preference, wish to live in a group setting? How would the associated confines of institutionalisation be separated from, for example, a co-living situation?

Professor Roy McConkey: The Deputy raised an important point about how we manage the transfers of people from congregated living, and how we prevent other people going into those settings. We have a lot of international experience on how to do this, and how it can be

done well. It requires what is called “bridging funding”. In addition to maintaining ongoing costs of service provision, additional moneys are needed to develop new styles of services that prevent people from going into such settings. That money is ultimately recouped, because the investments that exist in the congregated settings will be released through time. That can then pay back the bridging moneys that were involved in the first place. Some of that comes from the redeployment of staff. Additional staff are no longer needed, because current staff can be transferred to these new services.

There is also capital realisation. The National Health Service, NHS, in the United Kingdom has found this to be a lucrative source of funding, because it was able to sell off capital, such as large campus arrangements, which have often been recreated as housing developments in particular areas. Much money can be released over time.

The key strategy is very much looking at the future needs of people. Many people want to continue living with families and many families want to continue looking after their relatives. However, it is well-known that others will want and need alternative care provided for them. This requires forward planning. If one starts to do this before a crisis arises, then they can avoid getting into these emergency placements, such as in nursing homes or existing congregated settings. That planning needs to include opportunities for people to have accommodation in local housing, and the support that they will require. Some of that can be provided in the person’s family home. There may be options for people to continue living in the family home, with additional support staff and personal assistants coming in to help them. There are myriad ways of creating new styles of services around individuals that prevent the emergency crisis admissions, as well as finding ways of relocating people out of congregated settings. International practice tells us how to do it. Local jurisdictions have to find the resources to make it happen.

Professor Guatam Gulati: I thank the Deputy for the question. If I understand her correctly, she asked how we prevent trans-institutionalisation. The most important part in preventing trans-institutionalisation is recognising the presence of a disability. This is best done at the points of entry into a pathway. This includes asylum seekers in the reception process, people accessing homelessness services, at the point they enter homelessness services, and, more specifically, in prisons. Nearly one in three people in Irish prisons screen positive for an intellectual disability. Diversion programs have been ongoing for more than a decade, but in clinical practice, there is a large number of people with intellectual disabilities. To impact that, one has to recognise the disability and intervene at the start of the pathway, which is the arrest and custody stage or maybe even the pre-arrest stage. It is for the gardaí to recognise the presence of disability and perhaps think of a non-criminal justice response. That is likely to impact significantly the prevalence of people with intellectual disabilities in the Irish prison system. We conducted a study in which we brought together the views from multiple other studies of nearly 1,200 people with intellectual disabilities where they encountered police forces around the world. It made for troubling reading in that people with intellectual disabilities say they feel confused, frightened and perplexed and have great difficulty communicating at the point when they are arrested or are in police custody. When we repeated the same study looking at the views of nearly 1,000 police officers from multiple countries around the world, all of them said the same thing: they need more training because they need to be able to recognise the disability. Recognising the disability at the start of a pathway is the way to prevent trans-institutionalisation. I hope that answers the Deputy’s question.

Senator Erin McGreehan: I had to skip out to another committee meeting so I apologise if I repeat anything that has been asked. Reading all the witnesses’ contributions and listening to

this engagement has been worthwhile. I have seen issues from loads of different angles. After last week's engagement I felt deflated, having heard about the lengthy timeline for the depopulation of congregated settings. However, listening to practitioners, people who are directly affected and people such as today's witnesses gives me a little hope and a little knowledge as to how we move on. Overall, why do the witnesses think we are so slow? Where have we gone so wrong that so many among our population are seen and not heard, and how can we change that? The committee is dedicated to implementing the UNCRPD, but how do the witnesses see our role in that regard? What can we do on the committee to start advocating for what Professor Gulati talked about, which is people going into a prison setting and people potentially being put into an inappropriate congregated setting? Where can we now go to engage with the Department to ensure there is a triage between being diagnosed or treated and then being pushed into an inappropriate setting?

I was blown away by Ms Fitzpatrick and her beautiful brother. It was wonderful to hear such a positive story, but how do we provide that choice for everybody? Bubo is safe and in a community, as she said, and he is happy, but, as Ms Flanagan said, there is a lack of choice and a lack of personal assistants and there is so much work to be done. What are the witnesses' thoughts on that? They are to the fore of this. I thank them all because the discussion has been engaging.

Ms Lynn Fitzpatrick: I thank the Senator for acknowledging my being here for Bernard. To answer her question as to how we can look after everyone, that is what I advocate for. I advocate that there should be a full range of choices to suit every individual person. I am not trying to remove rights from anyone. I struggle with the fact that when this policy started there were 1,200 or so young people with disabilities in nursing homes who were identified in 2007 and it was said they were "outside the scope". My brother is so happy where he is yet he was prioritised to be moved out ahead of some people who may want to go. There should be a full range of options. I read a thematic study on the UN convention and it said equal basis means the right to accept or reject all kinds of living situations and all kinds of care, including institutional care. I do not consider that that is what my brother has. The reality is that the people I am here for today - and I wish there were a way I could bring committee members down to meet them and see for themselves - have nothing in common with the majority of people with disabilities. Of course, community living is right for the majority of people with disabilities because they have more in common with regular, ordinary - to use the policy terms - communities than they do with the people in St. Mary of the Angels, but the fact is that they exist. In 2019, 23 people were either admitted or readmitted into congregated settings. Some 82% of them had high or intensive support needs. As of January 2020, 1,953 people remained in congregated settings. That number has since increased because of admissions. Some 76% of them have a high or intensive level of support needs. Why are we pushing people out of these situations and into communities when it is well documented - if members listen to the radio, they will hear families say it every day - that they do not have the facilities to help them?

I have given a lot of time listening to everybody. Two things keep coming up: "nothing about us without us" and paternalism. I want to talk about how the policy has treated Bubo in this regard. As for "nothing about us without us", the working group on congregated settings came together in 2007, the policy was published in 2011 and then launched as a strategy in 2012. My family and Bubo did not know about the policy until September 2016. We found out about it because my mother received a phone call from one of the managers in Bubo's home out of the clear blue sky that summer telling her that his name was on a list for a state-of-the-art house in Milltown. We ended up having to try to dig and find out what was going on and to edu-

cate ourselves about this policy, which took us time. “Nothing about us without us”? Bubo’s family and all the families in St. Mary of the Angels did not know about this policy, but that is not the point. Paternalism has been talked about as well. Bubo cannot speak for himself, unfortunately. I wish he could. I wish he could be here instead of me. However, there are people in St. Mary of the Angels who can speak for themselves, who have sat in rooms with disability advocates and who have told them they want to stay where they are. They have said, “I love my home”, “This is my home” and “I do not want to move”. What is more paternalistic than a national policy that tells them, “We know what is best for you, and you will be way better off in the community”? On what planet will Bubo be better off having the same access to services and facilities I have when he needs hydrotherapy and supports that are not available anywhere else? He needs a team of specialists around the clock. The people I am talking about have very high care needs. I just wish there were a way I could get that across.

We need to be clear that there is a difference between a right and an obligation. I did not see the committee meeting last week but I know that the Ombudsman said we do not know whether people in nursing homes want to be there unless we ask them. If they want to be there, it is perfectly fine, but why is it not perfectly fine for my brother?

A reference was made to ten people in a single living unit. There are 63 adults in St. Mary of the Angels. There are 11 houses and chalets. There are no more than ten people in any single living unit on that campus of 30 acres. There is loads of development and loads of people who want to support it. We have been told we cannot develop on the land because of this policy and that the land cannot be developed because everyone has to move out. I feel there is a target on the back of St. Mary of the Angels because the policy says that to fund decongregation, these assets need to be sold off; by the way, these assets were donated to people like my brother by a local Kerry family and built from the ground up by the people of Kerry, so nobody has a right to sell them. I am sorry. I do not mean to be so heated, but it has been very difficult for me to sit here and listen to some of what has been said today. How can someone claim to be an advocate and to care about social justice and then be okay with people being forced - evicted - cruelly from their homes? I have the evidence of what has happened internationally, in Australia and America, when this same line of thought was followed. I can send that evidence on to the committee after the meeting. The data is there. To correct another figure from earlier, 942 people had been moved out at the start of 2020, not 600 or whatever Deputy Cairns said. That is not the figure. A total of 278 have been readmitted.

Ms Ann Marie Flanagan: I completely understand where Ms Fitzpatrick is coming from. What is worrying is when these policy decisions were made and the hospitals were closed down, we were promised community mental health care and that buildings would be sought and there would be investment in supporting people, but that did not happen. Through no fault of their own, people with mental health difficulties are on the streets and in our prisons. They become the target and they are seen as the dangerous people. They are seen as people without self-worth. The State must do better.

Ms Fitzpatrick is absolutely right. It is frightening for many family members. Where is the evidence that when we move people out of congregated settings that they will be treated equal to others? The Disability Act 2005 has never been commenced which is a disgrace on the part of successive Governments. The first line of the programme for Government uses health language to describe us rather than human rights language.

I cannot disagree with Ms Fitzpatrick in wanting to love and to ensure that her brother has everything he deserves. However, I do not agree that congregated settings should continue.

The State has an opportunity now, especially through this committee. I listen as much as I can to the witnesses who have appeared publicly. Those who appeared last week were enlightening when they challenged things like the 18 people. No more than Ms Fitzpatrick, I was moved last week.

The way numbers are thrown around with mention of millions of euro and statistics is de-humanising in terms of how we are spoken about. I completely empathise with Ms Fitzpatrick. She did listen because we were all being asked questions. Some of the solutions lie with getting the Assisted Decision-Making (Capacity) Act resourced and commenced immediately. In the case of Ms Fitzpatrick's brother, he should be asked with the people around him who support him. Ireland has been forced to move policies arising from international obligations and not because it chose to. That is an important one.

In this instance we are discussing disabled people. It could be people in direct provision tomorrow. It was the mother and baby homes a while ago. When we are discussing groups of people, we need to stand back and look at all of them and the systems that are causing them. It is easy now to have a focused conversation on disabled people, but actually we are the result of postcolonialism and of neoliberal policies under the capitalist idea of investing in someone if we believe that person can return the money to us. However, they have not given us an example.

I wish to share my own direct lived experience. I was 38 when I had my precious son. I waited for him. I am an earner and I own my own home. However, on the day Robert was born on 21 July 2011, the HSE and my service provider took nearly half my hours from me even though I had written to tell them I was having Robert. They wrote and they said they did not have enough money to provide the minimum support needed so they were removing all what they call social hours to 200 disabled people in County Clare. I spent my maternity leave campaigning publicly for myself and the other 199 people to ensure that they could have their hours. Because I am articulate, because I was able to self-advocate and because my child would have been at risk, which was not fair, I got a reprieve. However, I do not have a right to my services.

Ms Fitzpatrick is upset. When I go back there, that upsets me. I was so traumatised. For three years I was looking back to see if there was a HSE person or someone with the service providers. Is that sociable hours? Should Ann Marie be out with her baby? Should she be at the park? Should she be having coffee? That is the damage this does to disabled people when we do not have our rights affirmed.

Ms Lynn Fitzpatrick: I completely understand why St. Mary of the Angels would be completely inappropriate for somebody like Ms Flanagan who can be here today and articulates so well. I commend her on the work she does. Can we not just open our minds a bit to see that the disability umbrella is enormous and that my brother and people like him in St. Mary of the Angels are in the tiny minority? In trying to look after what is right for the majority, is there not a danger that we are imposing something on the minority that is not right for them?

I know Ms Flanagan said she disagrees about having congregated settings which is fair enough; it is her opinion. I would not be here today if so many disability advocates did not share that exact view. However, I did my best. I spent many hours writing that speech to try to paint a picture without pictures of what Bernard's life is like and what that place is like. Can she honestly tell me that it is an institution or that it is inappropriate? Does it sound inappropriate? People with fragile health are thriving and happy there and are not relying on medication or anything. I know somebody there who tried community living several times but it did not

work for them. Their life was saved by coming to St. Mary of the Angels. These things can also be true.

I am not trying to take anything away from the majority of people with disabilities, but it appears that they are trying to take something away from us. It is not because I am afraid of communities or all these things that have been said about me. It is not because we are all institutionalised and do not know any better. I know what is in the community. I know what is in his community. I plead with committee members to come to St. Mary of the Angels and see it with their own eyes and meet the people. They are all behind me today. We cannot see their families, but they are watching and counting on me in this very difficult battle for us.

Ms Flanagan mentioned how exhausting it is. I can tell the committee how exhausting it has been for my family and all the families trying to fight this policy on our own. To me it clearly violates many aspects of the UN convention, which is the topic of this meeting. I plead with everyone to step back and try to take another look.

Deputy Pauline Tully: I thank all the witnesses. We have had an engaging meeting with many different viewpoints put forward. It has certainly given me considerable food for thought. I particularly commend Ms Fitzpatrick. She has given a very good account of representing her brother and other people like him. She has made us think that congregated settings may not all be bad. They need to be assessed individually. It comes down to choice and what is best for the individual. Different home circumstances suit different people. That needs to be taken into account. All individuals need to be treated with respect and given that choice. That is what is most important.

Reference has been made to the Assisted Decision-Making (Capacity) Act, which is important. We had an engagement on it two weeks ago and we have been told that it will be implemented next year. Let us hope that timeframe is kept to represent those who have difficulty communicating.

Many families in my constituency have come to me. They want their relatives to live independently in the community and have applied for social housing because they are not in a position to buy something for themselves. They end up being accepted onto the social housing list but may be left there for up to 13 years. When I contacted the local authority to ask why this is happening, I was told it was not getting the commitment from the HSE to provide the supports the person needs to live independently. It cannot commit to providing the housing. It reiterated that it had the budget to provide the housing and will do so but it needs the commitment from the HSE. The last thing it wants, which has happened in a number of areas, is to provide the physical housing and for it to remain empty for three years because the supports have not been given to the people who need them. That is extremely important. Disabled people are also being forced to live with ageing parents who are not capable of caring for them, and should not have to do so. Disabled people want their independence and dignity and to live supported within their communities, but they are not being given the opportunity to do that. Time and again, when parents pass away the disabled person is put into a form of residential care that is not of their choice. That is heartbreaking because parents will have spent years worrying about what would happen to their disabled son or daughter when they passed.

Last week, we had an engagement on young people in nursing homes. The evidence shows that many of them were told that their placements were a temporary measure until proper housing could be sourced for them, but they had ended up spending years in institutions not of their choice. Some were forced into nursing homes and told the supports were not available to allow

them to live in their own homes. That is sad. The bottom line is choice and making the right choice for the individual concerned. I have been also approached by people regarding family members who have been placed in a congregated setting and are very happy there, as well as having their needs met. The UNCRPD is about recognising people's right to choice and supporting them in that choice.

The argument I hear constantly from the HSE is that it does not have the funding to provide the supports to allow people to live independently. Professor McConkey mentioned that it costs more to house people in a residential setting or nursing home. I have asked often if that cost analysis has been done but I have never been given a direct answer. I would be interested in getting a comparison on costs in that regard.

Chairman: Dr. McConkey can take the first question and I will then bring in the other witnesses for their contributions on the Deputy's points.

Professor Roy McConkey: The Deputy made two important points. The first point was that housing and support need to be co-ordinated. The lack of co-ordination has been one of the biggest flaws in the British system, with which I am most familiar. In the North, it has also caused a lot of difficulty for us in trying to create alternative living arrangements for people. The Departments began liaising when the importance of co-operation was pointed out to them. One of the purposes of this joint committee is, I would think, to hold two Departments to account on this particular issue. I understand the committee operates cross-departmentally and it has the right to do that.

The second point related to families seeking assurances in regard to where the future lies, which brings me back to the point I made earlier that people not wait for a crisis to occur to ensure that the services are starting to think about the longer-term arrangements for their relative. Families can be reluctant to do that because it involves parents facing their own mortality. Professional staff are also wary of doing it because they think that creates an obligation on them to fulfil those plans. The family will not necessarily want the plans to be enacted straight away, but they will want some sense of the direction of travel they are going in. That provides an opportunity for people to be creative in the solutions and steps that might be taken along the way, some of which can be low-cost steps.

Deputy Tully spoke about cost effectiveness. We need to be more open in service provider land and spell out the spend of costs for individuals in, for example, nursing home care and look at how that could be translated into personalised support hours that spend would provide for an individual. In more general terms, I would caution that international experience shows there are risks in perpetuating congregated care, notwithstanding that are some good examples such as those outlined by Ms Fitzpatrick. History teaches us that in congregated settings there are three risks. First, there is a greater of abuse of people who live in congregated settings. Second, there is a greater risk of them getting infections and, therefore, having physical illnesses as well as emotional problems and, third, which we have documented for Ireland, people in congregated settings die at an earlier age than people living in other settings such as with family carers. Some of that might be due to the risk of infection. In the United Kingdom, the number of Covid deaths in congregated living arrangements has been much higher than it has been in other arrangements.

In terms of policymaking, we cannot ignore the risks of perpetuating a policy as well as denying people their opportunities for rights moving forward.

Chairman: I invite Ms Flanagan to respond.

Ms Ann Marie Flanagan: Most of the points raised have been covered, but I want to add that for the past 20 years we have had the national disability strategy and we are supposed to have cross-departmental co-operation. That might happen at a higher level. People are burnt out from the number of committees discussing the lives of disabled people. Most of them are not disabled people and their families and that is problematic. The block funding of organisations is causing the HSE to be strapped for cash.

There was reference to the disability database last week as well, as if it were going to give us the answers to the needs of disabled people. When individuals and family members are asked if they want options that are all within the segregated institutionalisation approach, be that day services or residential care, people might think that is what their relative needs but because there are those of us who are able to articulate for ourselves that is a whole different arena even though that, too, is difficult. For people who need support to communicate and to envisage their best life offering them all forms of institutional segregated care is not offering them options. Who in Ireland has ever turned to a 23-year-old man with an intellectual disability and asked him if he would like an independent living support package or what are his dreams and ambitions? We use reductionist language by being realistic, and by smirking almost at the idea that somebody wants to get married, to have his or her own home and children. We look at risk and at minimising the choice of the person. We opt to provide disabled people with a particular type of support with the intention of looking at independent living in the future. The first option is to put them into residential care. We are now changing the language and using words such as “community”. I am worried about the language that is being used around community settings. If a person is living in a situation with two, five or more people that he or she has not signed a tenancy with, that person is not in control of paying the bills, his or her supports or recruiting who helps him or her.

I recently spoke with a person who works as a support worker in a disability organisation that supports people with intellectual disabilities in community homes. Support workers are moving from house to house on a shift basis. Let us think of the psychology for the workers. They do two to three shifts per week in one home and they then move to do the same in another home. They are working with people with severe intellectual disabilities and behavioural problems who are non-verbal. Their needs as employees have to be met as well. We are not building the supports around the individual in respect of his or her will and preference and what he or she likes to do and needs. We are educating unqualified people to manage medication so that if an individual’s behaviour goes beyond what is appropriate and safe for the staff, he or she can be sedated. Where are the human rights with regard to disabled people in that respect? I agree that there is plenty of international evidence that certain approaches in congregated settings lead to abuse. Even in Ireland, in the 1990s we raised the issue of protection in legislation that restricted the rights of disabled people to have intimacy. We know this came from worried families whose relatives were being sexually abused in congregated settings. Let us protect them. I do not know how prevalent it is now but we know that young girls have been forced to control their reproductive rights in case they get pregnant if they are abused. This is the depth of the risk of abuse that is happening when we do not look at the human being and see they have feelings equal to the rest of us. This is the part that has led to the level of institutionalisation and the normalising of it.

I am not in any way referring to the wonderful experience Ms Fitzpatrick’s brother and others are having. I am speaking about the majority of people who have been institutionalised

for years, whether it is disabled people or others. We dehumanise them. We separate them. We need to look at the consequences for the general population. One thing is to make sure proper services are provided for disabled people. I also want Margaret, John and Frank who have an intellectual disability to be able to go into a shop and be spoken to. I want them to be able to go to Citizens Information Centres and get information.

I work with many families. A 23-year-old son in a family might have been diagnosed with schizophrenia. He might be three years into a degree but has had to take a break. Because of societal ableism and the idea that people with mental health issue or disabilities are “less than”, many family members think such people have to be cared for for the rest of their lives and will never have a quality of life whereby they can function and be supported. The starting point with a son or daughter with mental health issues is to ask what they can do to care for them. We know this manifests in control and almost doing too much for the person. I work to support families to help them understand this stigma and understand they have to stand back and support their relative to have their rights and supports separate to family members.

The other point disabled people make the whole time is, dare I say it, that care is weaponised against them. Family members who want to have their needs and rights protected often use this against disabled people to keep them within the family and cared for. When we use language such as “caring for” people straight away we think that mother, father, brother or sister must know what they are talking about. No one ever goes to that family to ask how to help all of them to have autonomy and equality to the degree it is possible for them.

I spent a few days with relatives with whom I have a very loving relationship. My 23-year-old cousin has a significant intellectual disability. He communicates differently. He does not use words. He is non-verbal. My goodness is he well able to communicate what his needs are. He has a significant intellectual disability. What was really fascinating in the beautiful relationship I have with his parents is during our conversations it never dawned on them that he should have his own personal supports. They never thought they could go on holiday together when he would have someone to help him, rather than the idea of always going into residential respite. Of course he will go for that because it is the option available but we do not look at families and see how they can be together and how a person with significant impairment, including intellectual disability, can have support in his or her own right. That person can be treated equally to his or her brothers and sisters.

Ms Lynn Fitzpatrick: I acknowledge what has been said. I am the same as everyone here. The collective Irish psyche is damaged from years of institutional abuse. It is horrific. As I said at the beginning, my brother has never lived in an institution. It is very wrong that this is happening to his home and community and to the model of care that is so appropriate for some who do need care. Like it or not, they cannot feed themselves or do anything for themselves. This is the reality. There has also been desperate abuse. We all heard about the Grace case. When we first found out about the policy I asked what would those families do who for one reason or another could not keep their children at home when all of the congregated settings were closed. I asked where would those children go. The answer was into the foster system. If everybody is comfortable with that great but I am definitely not.

Abuse can happen anywhere. If people go to the St. Mary of the Angels website and look at the international page they can see the litany of failures in the group home community living model in the United States and Australia and what happened to people when they were moved out. I commend Ms Flanagan. She is an amazing advocate for the majority of people with disabilities. Sometimes I feel like this policy thinks people like my brother will go extinct. They

will not. There is no proper advocacy in Ireland for people such as my brother. We are trying. I am not an activist. I am doing my best to fight for these people because nobody else who should be, and who is funded by the State to do so, appears to be doing so. I really hope the committee takes stock of what I have said. I plead with it to do so.

With regard to support, the people in St. Mary of the Angels are supported to enjoy the community. They are always out and about. A few months ago, my father and I presented to the Minister of State with responsibility for disabilities, Deputy Rabbitte, and representatives of the HSE. I thought it was so funny afterwards when my mother told me that while my father and I were totally stressed trying to present at yet another meeting, Bernard was in Muckross House and Gardens having tea and cake. I am delighted he was. I am delighted Bernard does not know, and I hope to God he does not know, that this is going on, that people have decided he is not living in the right kind of community and has no business being there and that he would be better away from all of the essential services he has had for 40 years, as if that has actually cost lives. Professor McConkey said there is evidence that people do not live as long. I read in the HSE progress report on the time to move on policy that people in congregated settings live equally as long as their counterparts in the community.

Professor Guatam Gulati: I echo some points made by Deputy Tully. It is not just about housing. It is not enough just to provide housing. For real meaningful inclusion there needs to be support with employment, location, and physical and mental healthcare. The Deputy also spoke about the right to choice. It is important to echo what Ms Fitzpatrick also said. Something I come across weekly is someone with a disability leaving prison. Everyone, including the people themselves, do their best to psych up to this important point in their lives when they leave prison. Two or three weeks later, they have returned to prison. When we ask what happened we find that in reality their choices are restricted. They say their choice was to sleep outside where it is really cold or to break a window and come back to prison where at least they get a roof over their heads and three meals. In reality the choices are restricted. This is all I have to say.

Chairman: I thank our members. I thank Deputy Tully for chairing the earlier part of the meeting. I really appreciate it. I thank the witnesses who came before us for an extremely thought-provoking discussion. We have listened to the language of decongregation and institutionalisation. We have also listened very carefully to Lynn Fitzpatrick's very personal testimony. At every stage in our history if we had had that type of challenge to our thinking, and to the policies being prescribed over the years, we may have been in a better place with regard to providing for people with disabilities. Everybody has a different story to tell. This is clear from the evidence we have heard today. The great phrase of throwing the baby out with the bath water has to be thought of at all times in how we try to influence policy as a committee. We have heard very powerful personal testimony and it took fierce courage to put it out there in the public domain with regard to Ms Fitzpatrick's brother and family. I know there is excellent care in St. Mary of the Angels. I do not live too far from it and it is well-renowned throughout the area. We must challenge what has happened in institutions and to try to find what is right. We are charged with overseeing the implementation of the UNCRPD and to try to make sure that disabilities are to the fore. It is safe to say that the members of this committee, in the nine or ten months of its existence, have left their political colours outside and worked together to try to ensure we are doing the right thing for people with disabilities.

Today's discussion has been extremely thought-provoking and we will be reflecting carefully on it. I thank everyone involved, including the advocates, those who have given personal

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testimonies and the professors, for their honesty and forthrightness in putting information before us. We have no doubt but that we will be coming back to them for further information. I encourage them to keep up the good work they are doing in each of their spheres. We look forward to working with them. I also thank the committee members and our team for today's meeting.

The Joint Committee adjourned at 2.21 p.m. until 9.30 a.m. on Thursday, 8 July 2021.