DÁIL ÉIREANN

COISTE UM CHÚRAM SLÁINTE SA TODHCHAÍ

COMMITTEE ON THE FUTURE OF HEALTHCARE

Dé Céadaoin, 5 Deireadh Fómhair 2016

Wednesday, 5 October 2016

The Select Committee met at 9 a.m.

MEMBERS PRESENT:

Deputy John Brassil,	Deputy Billy Kelleher,
Deputy James Browne,	Deputy Alan Kelly,
Deputy Pat Buckley,	Deputy Josepha Madigan,
Deputy Joan Collins,	Deputy Hildegarde Naughton,
Deputy Michael Harty,	Deputy Louise O'Reilly.

DEPUTY RÓISÍN SHORTALL IN THE CHAIR.

The select committee met in private session until 9.13 a.m.

Inequality in Access to Health Care: Discussion

Chairman: Good morning everyone. I wish to remind everyone in the room to turn off their mobile phones or switch them to airplane mode as they interfere with the sound recording equipment. I welcome everyone, particularly viewers who are watching the live streaming of our meeting this morning.

In establishing this committee, the Dáil was giving recognition to the fact that there are considerable shortcomings in our health service. A big element of that is the two-tier nature of the service and the expense involved in getting access to services, whether one is a public patient or paying for services through private health insurance. There is a genuine shared hope among committee members that we can do something worthwhile and can take the key strategic decisions which will enable us to move from the current somewhat dysfunctional two-tier health service with all of its problems to having a modern, accessible, single-tier health service.

In our first session today we will meet Dr. Sara Burke, research fellow at the centre for health policy and management, Trinity College Dublin. Dr. Burke will make a presentation on inequality in access to health care. I wish to take this opportunity to acknowledge the input to our earlier planning sessions of Dr. Burke's colleagues from the aforementioned centre, Dr. Steve Thomas and Dr. Catherine Darker. In our second session we will meet representatives from the Seanad Civil Engagement group, who will make a presentation on the importance of a citizen-centred approach to health care.

I wish to advise the witnesses that by virtue of section 17(2)(*l*) of the Defamation Act 2009, they are protected by absolute privilege in respect of their evidence to this committee. However, if they are directed by the committee to cease giving evidence on a particular matter and continue to so do, they are entitled thereafter only to qualified privilege in respect of their evidence. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given and are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise nor make charges against any person, persons or entity by name or in such a way as to make him, her or it identifiable. Members are reminded of the long-standing ruling of the Chair to the effect that they should not comment on, criticise or make charges against a person outside the Houses or an official either by name or in such a way as to make him or her identifiable.

I now invite Dr. Burke to make her presentation.

Dr. Sara Burke: Good morning. I thank the committee for inviting me here this morning. I really welcome the work of this committee, which is long overdue. It is the first time in the history of the country that any attempt has been made to reach a cross-party consensus on the future of our health services, particularly the development of a universal health system where access to care is based on need, not income.

The committee has asked me to speak on the issue of inequality in access to health care. As Deputies will know from their lived experience and from the constituents they meet every day, there are many inequalities in access to health care in Ireland. This country is exceptional in terms of the fragmented, complex nature of health care and in the unequal access to diagnostics,

treatment and care.

Internationally, when one refers to universal systems one is talking about an entitlement to package of care, that is, the health and social care services to which citizens are entitled. In Ireland, because we do not have a universal system, there simply is no such thing as a package of care. People do not know what services they are entitled to and accessing social and health care services depends on whether one has a medical card, a GP visit card, private health insurance, an ability to spend money from one's own pocket on health services, where one lives and what type of services one is trying to access. Decades worth of research shows that it is the poorest, the sickest and people with disabilities who find it hardest to pay charges no matter how small those charges may seem and who find it harder to negotiate access. Indeed, any of us who has accessed the system - and GPs in particular know this because they do it every day - knows how difficult it is to negotiate one's way through it. It is also the poorest, the sickest and those with disabilities who have to wait longest for care.

Medical cards, which currently cover about 36% of the population, are a proven pro-poor measure. They are a positive safety net for the poorest third of society. It is actually the poor, the sick and people with disabilities who do not have medical cards but who are on lower incomes who fare worst in terms of coverage and access. I do a lot of international work in Europe and with the World Health Organization, WHO, and when I present data showing that we do not have universal access to primary care, people do not believe it. We are absolutely unique in a European context in not having universal access to primary care. When I present data showing that 54% of the population has to pay, on average, €50 for each GP visit, people are really stunned by that amount. At the moment, 64% or two thirds of the population may have to pay up to €144 per month for essential medication. That is an awful lot of money out of anybody's income.

Technically, we do have universal access to the public hospital system - or at least we did - in that everyone is entitled to public hospital care. However, measures that were introduced, such as the €100 fee for accident and emergency departments and the €750 per year charge for inpatient care mean that people without medical cards often cannot afford this. Even if one does have free or without charge access to the health system - we are all paying for it in lots of different ways - the very long wait times for accessing public hospital care mean these public patients are denied access. This is further exacerbated in the Irish context by what is called our two-tier hospital care, which incentivises and pushes people into private care. The inequalities in access we have manifest themselves in different ways, people without free general practitioner, GP, care or a medical card delay or do no not go to a GP in the first place due to cost.

When people present at a GP, often she will often need to send them for diagnostic tests. The Irish College of General Practitioners, ICGP, told the committee last week that it has done comprehensive research showing the poor access for patients who could not afford to pay privately to access an essential scan or test. One part of its research showed that 10% of GPs had direct access to a MRI scan in the public system with an average waiting time of 22 weeks whereas all GPs had access to MRI scans in the private sector within seven working days. This public-private divide further delays diagnosis and treatment for people who cannot afford to pay privately.

When a GP decides that a person needs to see a specialist we know there are extraordinarily long wait times to access that appointment in the public hospital system. We hear these figures generally every month when the National Treatment Purchase Fund, NTPF, publishes them and when they come out they are in the news. What hits the headline is that there are approximately

450,000 people waiting for that first outpatient appointment. In a way that number is not the problem because that is probably the amount needed within any population of our size. The problem is the numbers waiting a long time. I updated the figures in advance of this meeting from the August figures which show there are over 74,000 people waiting more than a year for that first outpatient appointment and over 110,000 waiting six to 12 months and 95,000 waiting three to six months. By any international benchmark zero to three months is a reasonable time to wait, any time after that is too long. We have hundreds and thousands of people waiting too long.

When a specialist decides that treatment is needed, after this first outpatient appointment wait there are also long waits for this. Despite the efforts of the last Government to reduce waiting times for treatment, and they had some impact in 2012 and early 2013, there have been longer waiting times for all groups since then, except those waiting over two years. Nobody should have to wait over two years for either that specialist first outpatient appointment or that specialist treatment.

None of these points touches on the inequalities in access to community services such as home helps, public health nursing, physiotherapists, occupational therapists, speech and language therapy, mental health services mainly because the data is so bad or does not exist. The HSE has begun to collect it in some areas but only in the past year or so. That means I cannot present that time series data we have for hospital services but such services are equally if not more important than hospital services. There are huge inequalities in accessing these, often depending on whether one has a medical card and on the existence or capacity of a service in the area where the patient lives.

Part of the complexity of the Irish system is the result of the existence and overlap of private health insurance on the public health system. We are unique for a high income Organisation for Economic Cooperation and Development, OECD, country for the way we marry private health insurance and the public hospital system. We know that people who can afford to pay privately can get their diagnostic tests quicker, get to see a specialist quicker and if insured may be able to get their treatment quicker.

My current role in the Centre for Health Policy and Management in Trinity College Dublin is co-ordinating a Health Research Board, publicly funded, project called ‘mapping the pathways to universal healthcare’. In this project we are monitoring Government progress, or perhaps the absence of it, towards a universal health care system. Initial policy analysis work that we have done, which was published at the end of last year, found that despite the rhetoric and the intention of increased universalism between 2011 and 2015, there was in fact less, not more, universalism now than there was in 2011. This is due to the further increase in drug charges for people with and without medical cards, the introduction of lifetime community rating and the failure to reduce waiting times for access for public patients. The one exception to some progress on universalism was the extension of free GP care to those aged over 70 and under six years. We know internationally that insurance-based systems, such as those in the USA or the Netherlands, are more expensive and cause inequalities. In Ireland, 45% of population have private health insurance yet it contributes less than 10% to the overall health budget.

In the project in Trinity my colleague, Dr. Sarah Barry, is leading on a systematic review on the organisational challenges of introducing universal health care. Professor Steve Thomas, who the committee has met privately, and Bridget Johnston, are doing groundbreaking work on financial protection. This is the first time this work has been done in Ireland. Financial protection is a core component of the World Health Organization’s definition of universal healthcare

which in effect means that health and access to health care should not cause impoverishing or catastrophic health expenditure. The terms are quite technical and I will spare the committee the detail on them. Catastrophic, however, means that people are forgoing essential expenditure in other areas to meet health service needs, usually out of pocket payments.

Initial work we have done on quantifying the amount of out of pocket spending is presented in the accompanying graph. This does not count everything people spend privately on health care, it counts only what we were able to count. It showed that in 2014 Irish citizens paid €580 million more out of their pockets for essential, generally hospital care or drug charges, than they did in 2008. We are doing more detailed work using the Central Statistics Office, CSO, national household budget survey data. It went into the field again earlier this year but we do not have the data from that. We have, however, analysed the 2009-2010 data, exploring the extent of affordability of private health expenditure and what proportion of Irish citizens are financially protected, or not, when they access health care. We found that the poorest people who experience catastrophic levels of private health expenditure, almost 50% of the poorest fifth of the population reported unaffordable levels of private health spending. I have given the committee the breakdown of expenditure according to those income quintiles. Two interesting observations arise from this data, one is that the poorest 40% of the population spent most on private health insurance and the highest level of out of pocket, unaffordable spend from those with middle and higher incomes was on dental care. These figures come from a diary people keep of what they spent their money on so they do not catch unmet need. They catch only what people actually spend. We know that low income groups do not go to the dentist because of the barrier of cost.

Providing timely access to appropriate care for the whole population, which is in effect a universal health system, will cost more money and require more staff. Professor Thomas is studying workforce requirements and our current staffing profile as a basis for getting to universal health care. He is also reviewing potential areas for positive rationing. In other words, how we can use the resources we have more efficiently so that universal health care is affordable and deliverable.

The work we are engaged on in this project, 'mapping the pathways to universal healthcare', aims to devise tangible steps towards a universal health care system, work we hope will be of use to the work of this committee. Delivering a universal health system is a political choice which is in the power of the committee. It is a political choice that is a matter of life and death to some people. It can improve all people's lives, our quality of life and indeed our deaths. I wish the committee well with its work and am happy to answer any questions members may have.

Chairman: Thank you for the presentation. What are Dr. Burke's views on how this committee might determine the basket of care and what is the best practice internationally?

Dr. Sara Burke: That is a difficult question to start with. The White Paper on Universal Health Insurance spectacularly avoided dealing with the basket of care. I gave the committee a conceptualisation of what we are working on as the basket of care in co-operation with our WHO and European colleagues. We went for the put everything in rather than keep some services out approach - put in social care, mental health services, drug charges, emergency departments - because we have to start by knowing the entire basket of care. Then, it is political choices to decide who gets access to what. We could all argue that pretty much everything in there is essential health and social care. Therefore, having a broader basket rather than an narrower one is the way to go.

Chairman: I will invite members to speak in groups of three and bank the questions.

Deputy Louise O'Reilly: I thank Dr. Burke for coming here and for her presentation which, as ever, was incredibly informative. My first question relates to evidence the committee heard from Professor Allyson Pollock on universal access underpinned by legislation. What are Dr. Burke's views on whether it is preferable to put legislation in place and frantically work towards it or to incrementally build to a point where we are in position to put the legislation in place with the heavy lifting already done? While Dr. Burke could probably guess my personal views on it, I would be very interested to hear her view.

I view the NTPF as privatisation by stealth, and probably the worst form of privatisation, given that people are being told it is not privatisation and it is good for them. There is a back-log, and there is a role for outside providers to clear the backlog. I would be interested to know the extent to which Dr. Burke thinks it might be possible to switch off the tap of the NTPF and how quickly it could be done.

Bizarrely, I read on Twitter that there is another new structure in the HSE. I have not heard the rationale for it and I do not understand it. I am sure it has something to do with governance and accountability. Professor Pollock would have spoken to us about it. Although in Britain the buck stops with the secretary with responsibility for health, they have very much strengthened local accountability. Does Dr. Burke believe the structures in the HSE are fit for purpose? I hesitate to use that phrase given that I do not mean it necessarily in that way. I refer to the man-ner in which they could be improved. Would we be better to focus on more local accountability rather than high-level accountability, which is where the HSE is focused?

Chairman: What is the new structure?

Deputy Louise O'Reilly: The one Fergal Bowers very kindly tweeted last week. It was the first I had heard of it.

Chairman: Is it a national structure?

Deputy Louise O'Reilly: Yes. It is the overall national structure. When I asked the Minis-ter, he said it was to do with filling a vacancy at the level of assistant director general or similar.

Deputy Alan Kelly: The old structure with all the directorates is being merged and there will be only a certain number of people over-----

Deputy Louise O'Reilly: There will also be nine community healthcare organisations, CHOs, all of which will have their own internal structures too.

Deputy Alan Kelly: It is another layer.

Deputy Louise O'Reilly: There is another layer again, given that the CHOs will have their own internal structures. There is an awful lot of structure.

Chairman: And the hospital groups.

Deputy Louise O'Reilly: Yes, but the hospital groups do not match with the CHOs. If Dr. Burke could fix it for us, that would be grand.

Chairman: I had not seen it.

Deputy Joan Collins: I thank Dr. Burke. One of my questions was the one Deputy Louise

O'Reilly raised regarding the NHS legislation and whether it should be brought in initially. She was very adamant that it would have to be the case. The committee is established to be evidence based regarding what is the best health service for our country. Reports such as this are very important for us to see the evidence on whether private health care is good or bad. The item that strikes me is that out of pocket spending had increased since 2008 to €580 million. This was during one of the worst periods austerity and cutbacks that we have had, and people have had to fork out extra money along with it. Dr. Burke said if we went to the NHS style of health care it would cost money. How do we determine this cost if we are saving in some areas and having to pay in others, for example, the €580 million in out of pocket expenses? How and when do we know what the costs will be?

Dr. Burke mentioned more staff. Could she develop this issue? We are losing staff. How do we retain our staff? What is Dr. Burke's opinion? If we are processing the idea of a national health service - I do not know if the entire committee agrees - we will need resources and they must be put in place early to ensure we have staff in the future to retain them. Should the State pay for nurses' and midwives' training and insist they stay in Ireland for the following ten or 15 years and be embedded in rural areas to pay it back?

Deputy Pat Buckley: Many of my questions have been asked, especially the issue of accountability which Deputy Louise O'Reilly raised. It comes up over and over again. Dr. Burke touched on dental care. Poor dental care leads to underlying problems later, such as heart problems. We keep raising the issue that we are a cure society rather than a prevention society. Would Dr. Burke look at initiating it very quickly and start rolling out the schemes we used to have with free dental checks and care such as cleanings? It is a preventative measure on a huge scale. We probably have the worst dental record in Europe among young children, never mind adults. In her opening statement, Dr. Burke mentioned that while 45% of the population has private health insurance, it contributes to only 9% of the total cost of care. Could she explain more about it?

Dr. Sara Burke: I listened with interest to Professor Pollock very strongly make the case for NHS-like legislation. It is an issue. Do we go for the big bang reform or do it incrementally? Professor Pollock has been working on NHS legislation during recent years as a mechanism of undoing the breakdown of the NHS and the marketisation that has happened in England. It is specific to there. The bread and butter of my academic research is policy making processes. In the literature, there is the big bang legislative change, which is what the universal health insurance was planned to be, very much driven by then Minister, Senator James Reilly. Ireland tends to take the path of incremental change. There are other methods of doing it somewhere in between. What the committee is doing fits into what is conceptually written about in the literature as a blueprint method. The committee is reaching a consensus and developing a detailed plan, and there is a body of work to be done with the public, the heath service and politicians to deliver on it within a reasonable period of time. We have not come down either way. I do not know which is the best answer.

The committee is to produce its report early in the new year. It will not be able to say, on 1 February 2017, that we will have a national health system, universally accessible to all and free at the point of delivery. We simply do not have the capacity to do it. We do not have the resources or the staff in place to do it. The blueprint methodology of reaching political consensus is very important, but we must also reach a public agreement that we want a certain type of service. We hear all the time that Irish people are very discontented. Public services top opinions polls when it comes to things about which Irish people are most upset. If we want

European-style public services, we must start paying European levels of tax or PRSI to pay for them. Politicians, many of us carrying out research and leaders in the health system must win the argument that if we want really good public services, we must pay for them.

Part of my PhD involved looking at the National Treatment Purchase Fund. I agree with Deputy O'Reilly that it worked for the people who got treatment. If someone has been waiting for a very long time and receives their treatment privately, obviously that is good for that individual but it does nothing to solve the long waits within the system. We have seen it. It has been in existence for all the years in respect of which I have presented the committee with data and the figures have gone up. Yes, there is a role for the private sector to play in getting rid of that backlog but there are political choices to be made. Do we want to use elective capacity within the private system on an ongoing basis or do we want to build up the public hospital system to deliver that care? We need to build up the public hospital system to deliver that care.

I saw the report concerning the proposed structure. I think it was a draft report from Tony O'Brien concerning reorganising the top of the HSE. Colleagues of mine in Trinity College have done more work on it than I have but we can prove absolutely that most of alleged reform in Ireland over the past ten or 15 years has been just been reorganisation. Has that reorganisation improved service delivery? I think the large answer is "No". There have been improvements in health and social care provision but they have nothing to do with the reorganisation that has happened. I would advise against another reorganisation or restructuring and in favour of much more work on what can we do to improve access to services for people. In a way, that is what we are doing. The project in Trinity College involves looking at the barriers to access and how we can address them. There is an issue around local accountability and yet what were the health boards? Were the health boards a form of local accountability? We got rid of them. Do we really want to go back to having politicians decide? I would urge against further restructuring and reorganisation and in favour of really reforming the system.

I hope I have answered Deputy Collins's question on the NHS. The €580 million in the graph involved austerity measures introduced in successive budgets - the emergency budget in 2008 and thereafter. Among other measures, it involved taking medical cards away from those aged over 70. It always astounded me, particularly as we were mapping these over time, that people were taking to the streets on other matters but not the fact that we as citizens are paying hundreds of millions more for essential public health care than we did eight or ten years ago.

There was a very good question about how we cost it. It is part of what we are working on in the project, although it is not the specific aim of the project. I know the ESRI is carrying out some work on that. There is a big part of unmet need so we can cost demand or activity at the moment. It is very hard to cost private sector activity because we do not have good information on it and it cannot be got. We need a substantial piece of work on what is unmet need because we know there is a huge amount of it. It is a hard thing to do but we can probably do ballparks on it. We will lose some in certain areas that we gain in others so that €600 million can be got through progressive tax measures rather than people having to pay out of pocket.

We need more staff. I looked at the staff figures in recent days. They have been increasing since 2013. I cannot remember the figures but there are a few thousand more staff now than there were but we are just playing catch-up. We are still not at pre-austerity levels of staffing so there is a body of catching up to do. There is also the issue of meeting demographic needs never mind the unmet need about which we spoke.

Should we make people who train in the system stay here for ten or 15 years? My PhD was

publicly funded and I have said on the record much to everyone's delight that we should do so. If someone is educated with public money, they should be giving something back. It goes down like a lead balloon. There is good evidence from other countries that it does not really work. It is quite hard to keep graduates here so the trick is having a health system in which people want to work and where people are proud when they go to work every day and do not leave it really stressed and under pressure in the evenings. That is about improving our health system but also retaining good quality staff.

Deputy Buckley spoke about dental care. I am far from being an expert on dental care. Some of the most severe austerity measures early on involved cutting back dental care to people on medical cards and in the PRSI scheme. There is a huge body of work to be done in Ireland in terms of making dental care accessible to most people who need it. Anybody who has children needing orthodontic care will say that it is next to impossible to get that within the public system.

Deputy Pat Buckley: Been there, done that.

Dr. Sara Burke: It is very expensive and that is not caught in the figure of €580 million.

How would I explain how 45% of the population has private health insurance when it only contributes 9% of the cost? It is because private health insurance in Ireland largely insures someone for inpatient or day case elective hospital care. It does not cover most other bits. It does not cover outpatient care generally, outpatient appointments with specialists in the first place, the cost of drugs and most primary care payments. In effect, it is inpatient hospital insurance that people are scared into taking out because it gets them faster access. It can be seen from the figures that it is very bad value for money because it does not cover the cost. This shows that the public system is subsidising the private system because 45% of the population has private health insurance but the majority of the expense of health care is not paid for by private health insurers.

Chairman: That private health insurance only contributes 9% to the health spend is remarkable. From memory, I think 77% is funded through the tax system so it seems that represents more than three quarters of the health spend. That should be the starting point on which we build.

Deputy John Brassil: I thank Dr. Burke for her presentation. Could she expand on the statement that private health insurance contributes only 9% to the health spend? It does not seem to-----

Chairman: This was raised with us initially by the ESRI when it presented a pie chart showing the different elements of health spending.

Deputy John Brassil: And that is the contribution that private health insurance makes?

Chairman: Yes, to the total health spend.

Deputy John Brassil: And the rest of the money goes on-----

Chairman: From memory, 77% comes from taxation. Out of pocket expenses-----

Dr. Sara Burke: Does 16% or 17% get it to 100%?

Chairman: We can get that chart.

Dr. Sara Burke: That is the ESRI data.

Deputy John Brassil: That is a fairly significant fact. Looking at Dr. Burke's figures, if 37% of the population has medical cards and 45% has private health insurance of some sort, that would mean that 18% has nothing. These people do not have medical cards or private health insurance. This means that close to one in five people is in a very vulnerable position. Will Dr. Burke comment on that, assuming I am reading her figures correctly? Does Dr. Burke believe a better system would be for everything to be free or does a small charge act as a disincentive? I work as a pharmacist and I give the example of the prescription charges. When they were introduced initially, the charge was 50 cent per item up to a maximum of €5. My experience of that was that it did not disincentivise anybody from getting their medication. However, when they were paying 50 cent for them, people who did not want certain items on a monthly basis said they did not need them, so it actually saved some money for the system. Increasing it to €2.50 an item up to a maximum of €25 is a disincentive, but the small charge was not. I am interested to hear Dr. Burke's opinion on the entire suite of services. Would she have an issue with a small charge or is it something that could be considered?

Third, the Canadian model was mentioned a few times last week, which is a very good example of a universal health care model. The other side of that, however, is that prescription charges, dental care and home care are not covered. People go to the private market for that level of cover. Does Dr. Burke believe there is a role at some level for private health insurance to assist in the delivery of an effective health system?

Chairman: To clarify the Deputy's question about the division of health spend, we have figures for 2013 which indicate that 77% of total health financing was from taxation, 12% from out of pocket expenditure, 9% from private health insurance, and 2% from private corporations.

Dr. Sara Burke: That 2% is probably private corporations paying health insurance for employers.

Chairman: They are significant figures.

Deputy Michael Harty: I thank Dr. Burke for coming before the committee. I have been reading her writings for many years. I am a general practitioner, GP, and I understand intimately the problems faced by the health service. I have a number of questions. First, how significant are staff shortages with regard to the delivery of services? In particular, how significant are our work practices, both in general practice and within the hospital? I believe there is a huge gap between primary and secondary care, and a lack of integration, communication and information technology? How significant are those factors?

Second, does Dr. Burke believe that primary and community care have the capacity to take on a significant increased workload in chronic disease management? Can it be an equal partner in the primary care-secondary care interface? With regard to reconfiguration, which Dr. Burke said probably has not led to much improvement in the health service, reconfiguration went ahead without actually reconfiguring the services to a new location. They closed down services but they did not put them into the centres of excellence.

Deputy Hildegarde Naughton: I thank Deputy Burke for her presentation. I have two questions, one of which is on using the metric of life expectancy. I understand Ireland is ranked 25th in the world with regard to high life expectancy. Japan and Singapore have higher rates of life expectancy, but on the suitability of using that metric when we discuss health inequalities,

is it accurate? Is it a useful tool?

Also, on the issue of geography, a Harvard study found that race, poverty and ethnicity are key divides between ill-health and wellness, and that geography is often a factor that is not taken into account when we are considering them. From an Irish context, could Dr. Burke expand on the way geography impacts on people's wellness and their ill-health?

Dr. Sara Burke: Deputy Brassil started by doing the sums and working out that one in five people are vulnerable. I tried to update the no cover figures for him. I had no cover figures in the second slide but I did not put them in because, like everything in life, it is more complicated than it looks on paper for a couple of reasons. There is a proportion of the population which has both medical cards and private health insurance, but currently we only have good information on the over 50s from the TILDA data. There is old data which shows that for the entire population there is a 5% overlap between people with medical cards and people with private health insurance, but we also know that is much higher for older people and it progresses. The older they get, the more likely the overlap, particularly during the time when all those over 70 had medical cards, so any estimates we have for no cover are only guesstimates. Also, some people have free GP care and also private health insurance.

We can say there are people who do not have any of those who definitely have more difficulty accessing the system but everybody is vulnerable at a point in time. Even if someone has the best private health insurance package that might cover them for high end hospital care, and they are back in the community, they might not get public health nursing or access to those basic public health services within the Health Service Executive, HSE, primary care team because they do not have a medical card. It is not as simple as saying there is one group of people who fare badly. Everybody is vulnerable at some stage, but we know that the poorest, the sickest and people with disabilities fare worse and that those without a medical card have the greater difficulties. Everybody has difficulties, however, because if they are waiting 18 months for that first specialist appointment, that puts them in a very difficult position.

The next question was on charges. I am interested in the Deputy's observations about the difference between a 50 cent charge and the €2.50 charge, which is capped at €25. The evidence internationally is that no matter how small the charge, it deters as much necessary as unnecessary use. Charges do deter use, no matter how small. I do not know the details of the dental or the GP charging literature off the top of my head, so I will not pretend to. I understand Dr. Josep Figueras will present to the committee next week and that might be a question to put to him in terms of application to the other areas but also in terms of the next question on whether private health insurance can assist in any way.

The problem with examining systems in other countries is that they have very different systems. In France, one's care is covered generally by a social insurance system but there is also supplementary care by what is a form of private health insurance, namely, a not-for-profit private health insurance. However, that is very different from the model we have here. In terms of our model, if we are moving towards using public money in the best possible way, private health insurance should only cover someone for privately delivered care. It should not cover what is subsidised within the public system.

Deputy Harty asked if staff shortages had an impact. Of course they have an impact. The Deputy sees it every day, but people experience it every day when they try to access services. There is a range of services people cannot access because of the long waiting times or the services not having somebody in a particular area. I refer to undoing the severe austerity cutbacks,

but even if we got back to 2007-08 levels we still do not have the public health system GP staffing requirements to meet current population need. We must significantly invest in staffing. Investing in public health systems is a very productive economic measure because it provides jobs for people in their own communities who will then spend in their own communities. It should be viewed as a positive spend and a resource rather than as a drain on society.

There is significant scope. Better than any of us, Deputy Harty would understand the need for changed work practices and how secondary care always seems to get preference over primary and community care. Staffing needs to be built up in primary and community care particularly. Since that sector does not have the capacity to take on more work, we need more people, but we also need to be doing things differently. We are beginning to see that happening. Colleagues of mine in Trinity College Dublin costed the role of specialist epilepsy nurses in the community. That work showed that, if someone with epilepsy had a link with a specialist epileptic nurse, it reduced or, in some instances, eliminated hospital admissions and the person stayed in work and was able to manage medication better. This was a much cheaper and better quality of life for the person with epilepsy than if he or she had to go to hospital to see a specialist every time. We need to be doing this for all chronic diseases. General practitioners, GPs, need to be paid to manage chronic diseases in the community, as do specialist nurses, occupational therapists and other health professionals.

I agree with Deputy Harty on reconfiguration. We have done a dreadful job of reconfiguration or reorganisation no matter how one looks at it. We shut down units, especially in rural hospitals along the west coast, without beefing up services there or in the major centres. Unsurprisingly, we are seeing the payback for that, for example, the level of demand placed on the emergency department in Galway or Limerick. That is what happens when one stops some services without beefing up others, in particular primary and community care. Had these services been resourced better, we would not have had some of the problems we have experienced.

Deputy Naughton's first question was on life expectancy and whether it was a useful tool. It is, but health services and access to same only contribute a small amount to life expectancy. They are important if one is sick and needs care, to quality of life and to outcomes. Forgive me, as I am only four days back from maternity leave, so I do not have the figures off the top of my head.

Life expectancy is a useful figure in terms of inequalities in health. One of my first policy jobs was in the Institute of Public Health in Ireland where, 15 years ago, we produced data showing that people with poorer incomes had much lower life expectancies than people with higher incomes. There is a case for targeting. One needs to invest in education, infrastructure, housing and career paths in those areas, but one also needs a greater delivery of health and social care services. There is a role for these, not just for meeting the health needs of people in those communities, but also for acting as their employer. In recent years, there has been a run down of HSE-employed home helps. Often they were women from disadvantaged communities who provided care to people living near them. We have contracted out much of that care. Employing local people in what often are deprived areas is a good economic and health measure.

Did Deputy Naughton ask about ethnicity?

Deputy Hildegarde Naughton: Yes. I read the Harvard study, which examined race, ethnicity and poverty in terms of having an effect on whether people were well or had ill health. The report also stated that geography was often not taken into account when considering the

divides between those who were healthy and those who were not. Has Dr. Burke considered geography in the Irish context?

Dr. Sara Burke: There is no excuse for not taking it into account. It is named in Healthy Ireland: A Framework for Improved Health and Wellbeing 2013-2025. Addressing inequalities is a key priority, but there are also significant ethnic issues. Travellers have a life expectancy of ten to 15 years less than the rest of the population. Good health policy is about anti-poverty measures and employment measures as much as, if not more than, health services, but I was asked to discuss the health service aspect at this meeting. Health services have a role to play.

Deputy Hildegarde Naughton: Geography is key.

Dr. Sara Burke: As well as disadvantaged urban areas and, for different reasons, rural areas.

Deputy Hildegarde Naughton: I thank Dr. Burke.

Chairman: I wish to revisit a number of issues. Total health spend is approximately €19 billion, which puts us close to the top in Europe in that regard. The issue seems not so much to be about how much we spend but how it is spent. It does not necessarily follow that, if we are to have a universal health care system that meets the population's needs, it will entail much additional spending. Does Dr. Burke accept that it is a question of replacing the private health insurance spend and out of pocket spend, given that 77% of funding comes from taxation? It is down to finding mechanisms for replacing these two blocks of spending.

Dr. Sara Burke: Replacing them, but also spending money in a better way on what Deputy Harty referred to as changed work practices.

Chairman: Doing it differently.

Dr. Sara Burke: There should be a greater use of care assistants as well as nurses in the community and GP practices. It is about getting others to do the work that more senior doctors and nurses are doing now. We have begun using health technology assessments for new treatments and appliances, but thousands of treatments and appliances are provided within our system without evidence that they improve people's quality of life or health. We need more rigorous decision-making processes regarding what types of service are provided and how they are provided.

Chairman: We do not know the basis on which decisions are taken on the allocation of resources.

Dr. Sara Burke: No, although the Chairman would know better than most.

Chairman: Right. The other issue is that of restructuring. There is restructuring fatigue within the health service and the constant churn of the past 20 years or so has been disruptive. Each time that there is a change in Minister, there is a restructuring. As a committee, we must address the question of how our health services are structured and the administration of health. For example, our six hospital groups and nine community health groups are not aligned. Given that integration is critical in a well-functioning health service, it is difficult to know how we can operate and conduct an assessment or measurement of outcomes when these two parallel systems have not been integrated. The committee is grappling with the question of whether we should take on the issue of the current structure and recommend a restructure. Bearing in mind

what Dr. Burke said about the constant churn, this fundamental question needs to be addressed. How do we get integration and how do we measure activity and outcomes when never the twain - hospitals and community services - shall meet? What are Dr. Burke's views on this?

Dr. Sara Burke: I do not have the answer. There has been constant reorganisation since 2001 - the Eastern Regional Health Authority, the HSE and then a continuous change in HSE structures. I agree with the Chairman that the current structures are not optimal. That we have hospital groups that are not matching with community health organisations is problematic. I agree that we cannot ignore it, but we should not undertake just a reorganisation. Previously, the only thing that happened was the reorganisation, which did not improve how people accessed our health services or their experience of those services.

I do not know whether the committee has spoken to some of those within the HSE or internationally. Perhaps Professor Josep Figueras can talk to the committee on this issue again next week. There are many models around integrated care pathways and last week we were talking about care pathways for people with multiple morbidities. There is a growing international literature on that which is not necessarily about restructuring. It is about improving the patient experience and pathway through health services. What needs to be the focus is the citizen's experience of the health system rather than the top-down structures that we have, faulty and all as they are.

Chairman: The management and oversight of it can be difficult.

Dr. Sara Burke: Yes. There needs to be much greater accountability and oversight. The systems we have are the systems put in place by the Oireachtas with the Health Act 2004.

Chairman: I thank Dr. Burke.

Deputy Louise O'Reilly: I wish to raise the questions of structures. I do not want to get bogged down because I spent enough of my life dealing with them to want to leave them behind. I wish to raise the issue of local versus national accountability. I am aware of the Carlow-Kilkenny model - I am not sold on it as the be-all and end-all, as there are as many problems as there are fantastic things going on there - but there is a degree of local co-operation and local accountability that does not have any political involvement. On the structure, what exists, exists and as for trying to change it, I think the Chairman is correct that people have restructuring fatigue. Would it be more beneficial for us to look at what is there and try to build in the accountability, rather than change it? Should we try to structure accountability into the structures that are there already, rather than spending our time trying to devise another structure, which will simply sit on the system that exists at present and will not deliver the type of reform needed? We all recognise the need for reform but reform and restructuring are not the same thing. Is it a case of parking the restructuring and looking at accountability and of trying to build in accountability at a local level and facilitate the level of co-operation that goes on at local level? If one has ever hosted a conference for nurses, they will talk to one other about what is happening in their own areas and will learn from one other. A significant amount of that goes on anyway without anyone trying to facilitate it. Would we be better to ignore the restructuring that may or may not be required and has been done many times and try to build in more accountability at local level?

Deputy Michael Harty: On the question of whether change should come from the top down or the bottom up, if one takes a bird's eye view of the health service, hospital groups are organising hospital structures and how the structures work but the patients are out in the com-

munity and only come into hospital for a short period and they go back out into the community. Organising hospital groups is great for hospitals but it does not actually deliver care to everybody because most people are out in the community.

It was mentioned that in Kilkenny, there is a bottom-up approach in which the integrated care committees, comprised of people on the front line, deliver a service and stream patients into the hospital group in a structured way. Rather than people coming into hospital in an unstructured way, when local groups are in place the patients are streamed into hospital in a structured way. I would like to hear the witness's views on top-down versus the bottom up.

If the witness were a member of this committee, what would be the three game changers she would recommend?

Dr. Sara Burke: Deputy Louise O'Reilly referenced Carlow-Kilkenny hospital group. I am aware that a delegation from it appeared before the committee but it might be worthwhile for members to go down to see what they are doing and to witness the meetings where the GPs and consultants share information. The Minister has recently done that. I think it is really good practice. If one looks at what is happening there, it has nothing to do with the structure, because they have the exact same structure as anywhere else but it has to do with work processes that have been pioneered by GPs in the community and a couple of visionary people in the hospital. It has, however, taken decades to develop and it is not like they started to try to do this two or three years ago; they have been doing it for decades. That brings us to a useful point. This is about resourcing processes in order that it is not dependent on the goodwill of a few innovative GPs and hospital doctors. There is a GP and a hospital doctor who are married to each other and I bet that is crucial to the success of the Carlow-Kilkenny model. It is about putting in place the processes in order that they are resourced and that people are paid to take time out to work out what is the best way for Sara Burke. Does she need to go into hospital today or can she be managed at home or in the community for two days and then can she go in a planned way, rather than her ending up on a trolley tonight? That is the nitty-gritty work they do at those meetings. I think the effort is about resourcing those processes and putting them in place. The processes in Bluebell might be different from the processes in Carlow-Kilkenny or in the Beara Peninsula or in Ballinasloe. That is something about respecting the services but also the people and the needs within the local communities.

Chairman: The voluntary hospitals are involved as well.

Dr. Sara Burke: That brings us to the issue of the lack of accountability within our hospital system. We have introduced these hospital groups, which brings me to Deputy Harty's question on top-down or bottom-up. There are plans for the hospital groups to go to trust status and given the English experience of trusts, I do not think that is the way to go. Given that we have groups, there are significant issues because we have this mix of HSE-funded hospitals and voluntary hospitals and it is very difficult for the hospitals to operate at present. While they used to get their budgets individually, the funding now goes into the group but legally, the hospital chief executive officer or the board - depending on the status of the hospital - is actually accountable for how that money is spent. There are major difficulties with that at present. I think the bottom-up approach is a much more effective way to go. The really good example of that is the success of the clinical care programmes. It is the one area where we have had good success in improving both access and quality of care. This was pioneered by Professor Tom Keane in cancer care. He asked everyone working in cancer services how can we make cancer services more accessible and improve treatments so that our outcomes start reaching international standards. It was a very bottom-up clinician-led reform of hospital services. It needed political

accountability and the then Minister, Ms Mary Harney, making difficult choices about reducing cancer care from 30 to eight hospitals. I think the success lies in the leadership of clinicians and front-line staff rather than in monolithic top-down structures.

In response to Deputy Harty's questions on three game changers, I feel as though I am doing an oral leaving certificate exam. As I am just cranking up my brain after maternity leave and the answers are not at the top of my head, I will send him an e-mail.

Chairman: We look forward to receiving that e-mail. I thank Dr. Burke for coming in and being so generous with her time and sharing her expertise with us. Dr. Burke's input has been very helpful to the committee and we appreciate that she responded to all of the questions so well, especially appearing before us when she has only been back a few days from maternity leave.

The committee went into private session at 10. 20 a.m. and resumed in public session at 10.58 a.m.

Citizen-Centred Health Care: Civil Engagement

Chairman: I remind those present to either turn off their mobile phones or place them in flight mode. This is our second session and we are meeting representatives from the Seanad Civil Engagement group, who will make a presentation on the importance of a citizen-led approach to integrated care. At the outset, and as a formality, I remind Members of the long-standing ruling of the Chair to the effect that they should not comment on, criticise or make charges against a person outside the House or an official by name or in such a way as to make him or her identifiable. I welcome the members of Civil Engagement and invite them to make their presentation.

Senator Colette Kelleher: I thank the Chair for the invitation to present to the committee. I fully support the aim of this committee to set out a ten-year, cross-party vision for the future of Irish health care. I have been following the work of the committee closely, trying to keep up with all of the papers presented thus far, which is a challenge, as well as preparing my submission.

Before I get into the detail of the submission, I would like to tell members a bit about myself and my background. I am not an academic, although I did try to provide evidence and examples to support the contents of my submission. I am coming from the field, so to speak, as I have worked within the system for a number of years, trying to make it work, sometimes successfully, other times not. That is what I am trying to bring to the party this morning. My professional experience includes a chief executive role with the Alzheimer Society of Ireland, although I have stepped down from that position now. I also worked with the Cope Foundation, an organisation that supports people with intellectual disabilities. I worked with the Cork Simon Community for eight years providing support to people who were homeless. I also worked with the Daycare Trust in the UK in the area of child care and early years education. In addition, I worked as an advisor to Margaret Hodge, MP, for some years. I have worked in many different parts of the system. I am a qualified social worker, have an MBA and recently became a certified practitioner in change and consulting, which, in a sense, is what this committee is all about, that is, dealing with the stuff that seems obvious and really easy but which is so hard to do.

The Irish health care system has drifted from crisis to crisis for decades which is why we are here around this table. Both piecemeal and radical reforms have failed to transform it and now it really needs a new vision, purpose and focus, backed by political consensus, as reflected by the membership of this committee. My submission sets out nine recommendations on how the Irish health and social care system can be recast to become citizen centred. This is a really important shift and while it sounds obvious, it is really difficult to do in practice. It will require a significant shift in how we organise ourselves and how we think. At the core of each of my recommendations is a vision for a high-quality, universal, single-tier health and social care system that adequately meets the needs of all people living in Ireland. I will briefly take the committee through these recommendations and then focus my presentation on the area of social care.

To begin, I urge the committee to start its deliberations at first principles, stripping back the layers of the health and social care system and examining thoroughly the culture, values and rights that underpin it. The committee should set out a list of shared values capable of creating a culture of compassionate health and social care. These values are the glue that holds everything together. We have all seen situations where those values were not present, for example, in the Mid-Staffordshire NHS Foundation Trust in the UK, where all of the regulations and infrastructure were in place but basic values seem to have got lost in the system. Values are not just something to be included in a mission statement. They must be lived every day and should be discernible and tangible in the governance, leadership, management, training, education and professional development of staff in the health service. When one profession does not talk to another, it is not an issue of professional differences but of failing the person at the centre, the patient. A similar approach was successfully taken in Canada in 1984 and I urge the committee to look at how the Canadians went about building a powerful, strong and decent health care system. I am aware that the committee invited the Irish Health Reform Alliance to appear at one of its first meetings because that organisation has proposed the development of a values and principles-based approach to health care and that universal health care be enshrined as a right.

Several groups of citizens have been seriously let down by our health care system and over the next ten years we must tackle these stark health inequalities head on. The poor health of the country's 30,000 Travellers is a national scandal. Traveller infants are 3.6 times more likely to die than their counterparts in the general population. The suicide rate among male Travellers is 6.6 times higher than in the general population. Life expectancy for Traveller men is 61.7 years compared to 76.8 years for men in the general population, a difference of more than 15 years. For Irish traveller women, the difference is ten years. The director of the Irish Traveller Movement, Mr. Bernard Joyce, recently said that there is a direct correlation between Travellers' quality of life, physical and mental health and the quality of their accommodation. The state of some Traveller accommodation is truly shocking. There is a halting site at Spring Lane in Cork city, which is within walking distance of where I live. The lives of the people who reside on that site and those of the individuals who reside where I do could not be more different. The site was built for ten families but now houses 30. Traveller representatives have said that on the Spring Lane site many families have no water or toilets, some live in old damp mobile homes and all live with daily overcrowding. We all know the implications of overcrowding for things fire safety. One need only recall the tragedy that happened a year ago in Carrickmines. There are almost 100 children living on the Spring Lane site with no place to play. Peoples' health, mental health and life expectancy are suffering as a result.

Stark health inequalities also exist for other marginalised and minority groups. The average life expectancy of people experiencing homelessness is 47 years for men and a shocking 43 years for women. I worked with the Cork Simon Community for eight years and when I walk

around the city now, I do not meet the people I worked with in the past because most of them have died. Homeless people die young. Data shows that 60% of lesbian, gay, bisexual, transgender, intersex, LGBTI, people have seriously thought of ending their own lives, with almost half of these considering it in the past year. Younger LGBTI people are the most vulnerable in this regard. An estimated 30% who have attempted suicide did not access mental health services, with cost, stigma and lack of understanding of LGBTI issues cited as the main barriers. These barriers can and must be overcome. These are the problems, most of which we already know about. It is really important that the committee examines the gaps in access to health care for these groups of people, as well as looking at values. Health planners need to hear the voices of these marginalised groups, who live with the effects of health inequality.

In my submission, I propose the establishment of a pilot version of NHS Citizen and Healthwatch UK and I would be happy to answer any questions members may have in that regard. In addition, area-based, inclusive, stakeholder based health care planning forums should be established on a statutory basis for ongoing population planning. These would allow the voice of the citizen to be heard loud and clear in the planning process. I have seen at first hand in the UK how effective these can be. When I was working on child care, each local authority area had to produce a plan that was informed by children, parents and others. That plan was attached to targets and local authorities could not get funding until they submitted their plans. I have seen how well such planning forums work. The homeless forums that were set up in the early 2000s were also very effective. However, such forums will come and go unless they are set up on a statutory basis and sometimes what is missing from them is the voice of those representing people with disabilities or dementia, for example. These must be included in the forums and actively engaged with. I know that GPs from the Carlow-Kilkenny model of care made a presentation to the committee recently about their version of a health care planning forum. There are embryonic versions of these forums in existence already and they must be built upon. This is a practical suggestion and, as I have said, I have seen them work.

We cannot put together a comprehensive plan for the future of Irish health care without looking at social care too. In order for the health care system to function properly we also need to have a properly functioning social care system. Both health and social care are intertwined. When I talk about social care I mean provision to citizens of social work, personal care, home care, day supports, therapies, counselling short breaks and respite, support services to children or adults at risk and caring for needs that arise from disability, old age or poverty. If we do not develop social care, we will create a demand for acute care by default. We have not developed an adequate social care infrastructure or safety net in this country as yet. Development has been piecemeal at best. In many ways, social care is the Cinderella of the health care system. It is neglected and overworked and this is having a disproportionate effect on acute care. Social care services are patchy, disjointed, dysfunctional and too often paternalistic. It is based on the idea that one takes what one gets rather than what one needs or wants. In many cases, availability of services are determined by a postcode lottery. Regardless of whether citizens are living in Donegal or Donneraile and whether they have dementia, Down's syndrome or depression, they should be entitled to the same level of support that they require based on their needs at that particular time, and those needs may change. The supports people need at the early onset of dementia are very different from the support they need at the later stage of dementia. Supports need to travel with a person's needs as they develop.

There is no clear vision or plan in the area of social care. People working in the HSE, and people like myself who are on the other side, work hard but provision in this area is not coherent or joined up and it fails citizens. It undermines people's dignity. We were at the launch of

the alliance of organisations supporting the call for home care provision. Incontinence pads are now being rationed but that is not good enough and it is not necessary in a country like ours in this day and age.

Poor social care provision shortens lives and life expectancy. Up to now key areas of social care have been left by the State to poorly funded and, sometimes, poorly governed charities. As a result, very often citizens have to rely on services and supports which require fundraised income to operate. There are well publicised examples of core services for vulnerable people being delivered by charitable organisations that can be under question. Social care services for vulnerable people must be transparently commissioned, adequately funded and properly governed.

While I recognise that the State invests in social care, the existing spend is inflexible. I was responsible for an organisation and had very little scope to innovate and change things in response to people's needs. It was very fixed and tied up. There is little room in the budget for the expansion of services or even innovation. Of late, there have been some welcome moves towards personalised budgets in order that people can get control of their money and thereby decide what they want to do and how they want to spend it. I have been appointed to a reference group in that regard. On the whole, the budget needs examination and increases in key areas are also needed.

We should think of social care infrastructure as we would think of a transport system. For an effective transport system to operate, we need all the parts to connect and work together. We are unfortunately missing many pieces of the social care infrastructure. I am sure my colleagues, Senators Dolan and Black, will expand on that. Just as we are retrospectively joining up the Luas lines at huge cost and upheaval, we also need to join up the social care infrastructure to create webs of care. In the long run, just as in the case of the Luas lines, it will be a worthwhile investment.

One key part of that infrastructure is home care. A properly functioning home care system would and should serve people with a variety of support needs, including, but not exclusively, people with dementia. To take the example of that group as I am close to it, there are currently 55,000 people with dementia in Ireland, 63% of whom live at home and want to live at home. The national dementia strategy, co-funded by Atlantic Philanthropies, promised to provide 500 home care packages, a modest enough expression in that strategy. To date, only 72 people have benefited from those. That is 72 out of 55,000 people. According to the Department of Health, 25% of people in acute hospitals have dementia. Keeping them in that setting makes no sense. The national dementia strategy, just like A Vision for Change or Time to Move on From Congregated Settings and many other excellent plans in the social care sector, has become a victim of Ireland's implementation deficit disorder. We have good policy but we do not implement it.

In one week in August there were 31 people in three hospitals, ready to be discharged, who were waiting on a home care package. Over the course of the entire month of August only one home care package was provided in those hospitals. As a result, there were 30 delayed discharges. That is economic madness. An intensive home care package costs only €1,000 a week, while a stay in an acute hospital costs approximately €1,000 a night. If we scale that up over the year and across the State, the savings are significant. The Minister, Deputy Harris, told the Joint Committee on Health and Children last week that there are currently 629 people whose medical care is complete who are still in hospital because other necessary care, support or accommodation has not been provided. Remarkably, there has been a cut in the level of funding for home care over in recent years in spite of the need for it. Funding for it in the period from

2008 to 2015 has reduced by €11 million. That is despite the need, demand and unequivocal citizens' preference for it. A study published by UCD, Age Action, The Alzheimer Society of Ireland and the Irish Association of Social Workers incontrovertibly shows that people want to stay at home rather than being in other places. Approximately 22,000 thousand people have signed The Alzheimer Society of Ireland's petition on home care, which signifies there is massive support for this.

A similar picture could be painted in the area of people with disabilities, people with chronic conditions and older people. The lack of home care and other social care provision has many knock-on effects. People are too often forced to give up employment to take on caring duties full time. This burden predominantly falls on women. The 14% pay gap and 37% pension gap can be partly explained by women dropping out of paid work to take up caring duties because they simply had to do so.

Looking to the future, if we accept that the social care structures are not fit for purpose for today, the time for action is now. We have an ageing population. I have described what is happening in the here and now but matters will only get worse as our population ages. We should be celebrating the fact that people are living longer and that people with Down's syndrome are living longer, but they do not have access to early onset dementia supports, which many people in that group may develop. The fact that people are living longer is a cause for celebration, and not for angst, but we need to provide for them.

We need a comprehensive plan for social care, underpinned by compassionate values and rights, and informed by population planning and health forums. We need to dismantle old systems and shut down many of the institutions. I accept this project may be beyond the scope of this committee, and it may require a committee or commission in its own right. We must make it happen because if we do not adequately examine social care, all the rest of the work of this committee will be put in jeopardy. As a crucial first step, over the lifetime of this Government, we could significantly invest in home care. Such investment in home care must coincide with the introduction of robust regulation, a legal entitlement to guaranteed access and proper workforce planning. We do not want to have people providing that care at the lowest level of care. It is skilled work. When I visited the Brothers of Charity in Liverpool, I learned that 90% of its workforce were on the minimum wage. We need to do better than that for the people providing this skilled work and we know that it will result in long-term cost savings. We know there is a demand from citizens and we know that it is key missing piece of the social care puzzle.

The Taoiseach said this week in the Seanad that he wants "an Ireland that looks after its people from the time they come into the world to the time they leave". A transformative investment in home care will go some way to making this vision a reality. I thank the members for this invitation to appear before them and I welcome their questions.

Chairman: I thank Senator Kelleher for her comprehensive presentation. I also acknowledge the excellent submission she made to the committee some weeks ago. It is very good and I thank her for that. We will also hear from Senators Black and Dolan so who would like to speak first?

Senator John Dolan: It is ladies first always in our group.

Chairman: I call Senator Black.

Senator Frances Black: I thank the committee for inviting us to come along today. We

were all delighted to come. I want to speak on a specific issue of concern. I have worked in the addiction area since 2003 during which time I have learned a great deal, particularly from family members, about the impact of harmful drinking on families and particularly on children. We know that we have a huge problem with alcohol. Three people a day are dying from an alcohol-related illnesses, which is scary. Alcohol abuse costs the Exchequer €800 million a year. Approximately 1,500 hospital beds a day are occupied by people with alochol-related illnesses. Harmful drinking is a major issue.

I want to talk about the hidden harm element. The wide range of harms that are caused to children as a result of parental alcohol misuse is known as hidden harm. As the harm is often not publicly visible, that means that those children are often not known to the appropriate services and they suffer harm in a number of important ways that can impede their physical, emotional and social development. These children can suffer in silence and they often to do not know where to turn for help. The impact of a parent's harmful drinking has a deep and long-lasting impact on their lives that may not fully emerge until young adulthood and beyond. For a child, harmful parental drinking can shape their every moment from the time they wake up to the time they go to bed. A child worries about whether his or her mam or dad will drink that day, what mood they will be in and whether he or she will go to bed hungry.

A child can take on the role of a parent in the family, making sure brothers and sisters are fed and getting them dressed and out to school. In the most severe cases, a family situation can deteriorate to the extent where children are emotionally abandoned, physically or sexually abused or neglected with dirty nappies going unchanged and children going without regular meals.

I have conducted some research on this matter and found an amazing women called Dr. Stephanie Brown who works at Stanford University. She talks about the developmental impact of parental alcohol misuse on children's attachment and identity formation and the impact of alcohol misuse related trauma on all aspects of development. The earliest research emphasises the link between harmful parental drinking and mental health issues. This is the area in which I am specifically interested. We have found that children who are reared in homes where there is harmful drinking have a high rate of mental health issues and then we look at our suicide and addiction rates in Ireland. Children can go on to have alcohol or substance misuse problems themselves. Many researchers have found that children with parents who misuse alcohol can be more likely to experience symptoms of anxiety, depression or both, anti-social traits, relationship difficulties, behavioural problems and alcohol abuse themselves.

Children living with this trauma may develop a sense of self that is equated with defence. These defences are designed to keep the enemy out and to minimise anxiety, fear and the threat of humiliation. The defensive self or false self creates a deep sense of inauthenticity and a barrier to connectedness with others that exacerbates isolation and loneliness. The defensive mantle tends to be brittle, inflexible and self-reinforcing, with the potential to break down under stress.

Over time this cumulative trauma can engender trauma related symptoms such as depression, anxiety, hyper-vigilance, low self-worth and somatic disturbances such as head and body aches, chronic tension and so forth. It is shocking when one considers the evidence for all this. These symptoms, if left untreated, can become full-blown post-traumatic stress disorder, PTSD. They can lead to all sorts of life, learning, health, psychological and relationship complications and a desire to self-medicate. This is how the insidious baton of addiction gets handed down through the generations.

The problematic use of alcohol and other drugs is a complex issue and continues to be one

of the most significant health and social challenges facing society today. Approximately one third of the people are engaged in harmful drinking. I am not talking about addiction but a binge drinking culture. This issue affects families and communities. It can have serious implications for the welfare and safeguarding of children from conception and throughout their lives. Children living with the everyday experience of the problematic use of alcohol may experience incipient or traumatic neglect, physical and emotional abuse, a lack of appropriate nurturing and adverse outcomes that may affect their adult lives.

I do not want to be repetitive so I will talk about what we can do to prevent this problem arising. I have seen the effects of alcohol and substance abuse through the work that I have done, in particular with families. Therefore, I know it is important that we have effective prevention and early intervention for children living in homes with alcohol or substance misuse. The children who live with parents who have drug and alcohol problems are among the most vulnerable in society. It is imperative that we ensure the best possible start in life for every child through effective prevention and early intervention.

We must also establish a holistic, recovery-based education and therapeutic programme for the adult children of alcoholics. There is a successful programme in America and there is evidence available to prove how well it has succeeded. The development and maintenance of a therapeutic alliance**,** or a quality treatment relationship based on mutual respect, is an essential component of effective treatment for individuals who are adult children of alcoholics. Empathy, respect and belief in the individual's capacity for recovery are fundamental service provider attitudes and values. Peer support and continuing care is also an option.

This issue should be recognised. The culture of drinking in Ireland, particularly harmful drinking, has an impact on society in terms of mental health, addictions and physical harm. There is an evidence piece in America called the adverse childhood experiences study or ACE for short. It centres on the impact of dysfunction in the home and how it can have an impact on people on a physical level in the form of stress related illnesses like cancer and heart disease. It is important to consider the future of health care and recognise that alcohol and substance abuse play a huge role in the lives of children. The impact is not recognised in health care at the moment. That is why funding should be made available for people who have been impacted by parental alcohol and substance misuse. If we do so, it will prevent the legacy of mental health and addiction issues, and even physical health issues, that have been passed down through the generations.

There should be a consensus that integration between mental health and addiction services is sorely needed and long overdue. Again, we can talk about dual diagnosis. There is now a pressing need for transformation to recovery oriented care in both systems. As my colleague, Senator Kelleher, has said, we must all work together to provide intervention services. I hope I have not talked for too long and I am sorry if I did so.

Senator John Dolan: I wish to endorse the opening remarks made by Senator Kelleher on the valuable work done by this committee and the impetus it has given to a vital national issue.

I welcome the opportunity to make a short presentation to the committee. If people are confident that we have a robust and comprehensive health service, they will have the confidence to participate in the economic and social life of the country. This matter is bigger than health care. It has to do with having a sound fabric of health and active people in society, as best one can achieve doing so.

I will make a number of points that struck me having spent nearly four decades involved in the disability movement in one way or another. Disability, disabling conditions and chronic illnesses are not discriminating in who they affect. They cut across all areas of society: the young and old, people living in urban or rural regions, the well-off, those experiencing poverty and those who are close to poverty. Therefore, disability is a major issue for Ireland and is not a sectoral issue. The health status of a population is critical to a society's economy, social development and achievements.

I have observed that what we now term as disability, and I include mental health, is very different from four decades ago. It would be useful for me to refer to disabling conditions. We know so much and advancements have been made in health systems, diagnostics and all the rest. There are many conditions that can be kept under control by a range of treatments and whatever. Therefore, we must realise that we are all on a continuum between being wholly healthy and having issues and some very severe issues with restricted ability and reduced functioning. It is important that we realise there is no such thing as them and us. It is a fact of life that we are all on that slope and we should not be upset about it either as it is life.

Some people are born with disabilities but they do not make up a huge number of the overall population. Many people acquire disabilities over the course of their lives for a multitude of reasons such as injury, self-harm, lifestyle, a predisposition or what we might simply call, perhaps not too correctly, ageing. Some people can suffer more than one condition. For instance, there is a huge correlation between the number of people with Down's syndrome who will go on to develop a type of dementia. We did not know that 30 years ago because previously these folk did not live past 30 years of age. It is to be celebrated that they are living into their 40s, 50s and 60s, but we are wrong if we do not plan for people having longer lives and the other things that can happen to them. While people with disabilities and disabling conditions are a minority of the overall population, they are a majority in the use of health services. It is not just a numbers game. Some people rely on health services more than others, and people at a certain point in their lives certainly will.

Advances in information, knowledge, technology, treatments, earlier diagnosis and understanding of causal factors shape the environment in which we now operate. I believe we are not fully, or anywhere near, exploiting the opportunities and potential which all of these bring. There are still crazy situations where somebody almost uses a pigeon to take a letter from one place in the health services to somebody else. We are not exploiting simple things such as communications technology and the like. An improved health service will mean more people will survive birth, which is a good thing, but we must accept that there will be some babies and children with severe and complex needs. Let us face that fact and plan for it. In addition, as I mentioned already, people with such conditions will live longer. The complexity of health needs to be catered for will clearly also increase. These are issues we will have to accept as side effects of something that is good, which is more people being born and more people with disabilities being able to survive them and live longer, and confront that.

The future of health services must focus on, and invest strongly in, the areas of prevention, early intervention and amelioration, and the committee heard Senator Black speak about that in a particular context. If we do that, it can help to dampen further demand on health services. Getting in early and supporting people is the smart thing to do, even from an economic point of view. More generally, the current structures and delivery systems of services and the way society thinks about disability and chronic illnesses exacerbate rather than alleviate the associated problems. Our approach to how we plan services and think about things is dysfunctional

and very unhelpful. Services must be remoulded so that every person, in so far as possible, is able to self-manage and have a sense of control over their condition and living circumstances. Health professionals must be better able to optimise working in partnership with people, their families, support networks and the groups that work with them. Primary and community care infrastructure is critical to all of this.

Beyond that, it must be recognised that the success of the health and care services in supporting and responding to disability and disabling conditions is significantly dependent on factors outside of the health service. That is one of the shifts in mindset that is required. Events outside of the health arena have a huge impact. I recall meeting a man 36 or 37 years ago, who I still know, who is physically disabled and in a wheelchair. He could not push himself around and did not have a motorised wheelchair. He went to a special school and graduated from there to a special workshop in the same organisation. I lost contact with him over a number of decades, but now he has a motorised wheelchair. He lives on the north side of Dublin. Dublin Bus and the bus stops became accessible. We take the use of public transport for granted, but that meant he could get from his home to any place around the city when and how he wished. He could get to his place of training. In fact, during that time he re-trained with the support of the organisation. He went to a college of further education that was accessible and near to him. There are a number of fortunate accidents here, and that is what we do not need because we must create the situation so this can happen. That man is now employed in that organisation. Little things, such as a decent motorised wheelchair under his bum, an accessible public transport system and accessible spatial infrastructure, trebled and quadrupled the value of the supports he was receiving. That is what can be won here.

Accessible and available transport, including public transport, accessible public buildings and spaces, accessible information or information in accessible formats for people who are blind, deaf or have other conditions, good and appropriate housing, access to education, training and employment and sufficient income are equally as important as focusing on the health and care side. Both must be progressed if one wishes to maximise the results and returns. These areas must be planned for and improved in tandem with the health and personal social services. Every Department and public body has a role to play in creating the tapestry that will optimise the health and well-being of all of our people and maximise the participation of people with disabilities and disabling conditions. The health and well-being of all is a core matter for all of the Government, not solely for the Department of Health and the HSE. We can criticise the latter, and I am sure we will continue to do so, but it is and has been wrong to see all of the issues as being in the health area. The other aspects, such as education, training and access, are pieces of the jigsaw that have not been playing their part.

In conclusion, disability is not a sector in Ireland. We are all going in that direction and if we are not, our loved ones are. Nobody escapes this in one way or another. Consider it as making Ireland open to the broad spectrum of its people as they are and as they will be. It will be a very hopeful situation if we can do that. A small matter on which I have been working is the departmental strategy statements. It is important to get something into them, when they are being compiled under the new Ministers, related to this agenda of access for people with disabilities and disabling conditions. Every Department has something valuable to offer here. Rather than them saying they will see if they can do a special programme, the ambition must be to ensure that everybody can participate as they are, regardless of the shape they are in and their abilities.

There are three elements. What happens outside of the Department of Health is as important and in some ways more important, because that is where one gets the multipliers and the

real outcomes for people to be able to live. People with disabilities, their families and support groups should be supported and encouraged to be more at the centre of managing, controlling and being on top of their lives. Third is prevention and early intervention. There is no doubt that when we started slapping people with penalty points and raised their insurance costs fewer people died, thankfully, and many other people did not become disabled, with their families caught up in that, who otherwise would have. That is because of something that was done somewhere else.

Chairman: I thank the three witnesses for their comprehensive presentations. The committee is very pleased to have the benefit of the group's experience and expertise on the front line. There is no doubt that the Civil Engagement group has a huge amount to contribute to the work of the committee and we very much welcome the presentations and Senator Kelleher's earlier submission.

Most of the material the group has provided today feeds into the work of the committee. I would like clarification on a number of points. Senator Kelleher referred to stakeholder-based health care planning forums. We have been looking at the administration of health quite a bit, the geographic differences that exist and how health services are organised geographically. What does Senator Kelleher have in mind in terms of the Irish situation? What kind of area are we talking about?

I have a question on the role of charities. It is quite a problematic area in many ways and there are issues about accountability. Those questions were raised with us by Dr. Stephen Kinsella when he appeared before the committee. What is the Senator's opinion on the role of charities? What does she recommend to make the sector more coherent and accountable?

Senator Colette Kelleher: I have worked for charities both in Ireland and in the UK. Charities have stepped into the breach when the State has failed, but very often the State needs to take up where the charities began. Very often they have had to carry on and carry the can because the State has not been able to step in or take up its role. Charities have a great role to play in advocacy and innovation, but whether they continue to be a main provider will depend on the charity. A good commissioning framework is the way to deal with it. Charities are as good as what they can deliver to people. The confusion has arisen because charities have been advocates and have suddenly become providers. Some are well intentioned but not geared up to be the kinds of providers we need in a regulated and standards environment. Good commissioning, but not a race to the bottom commissioning, is the way it will be dealt with. It can be seen in the UK. Charities are coming and going based on what the consumer needs. Without a charitable sector in Ireland, some people would have nothing. It is now time to take stock, say the situation is historical and ask what the citizen needs. If a charity, private provider or the State can provide these services, it should be the right way to go about it. I hope that answers the Chairman's question.

Chairman: Does the Senator think there is a lot of scope for amalgamating charities?

Senator Colette Kelleher: Yes, absolutely, but the true role of charities is advocacy and innovation. They are things the State may not always be willing to do. If more charities could be in that space, there would be a healthy tension between the citizen and the State rather than the State becoming a service provider by default because there is nothing else out there.

In terms of area planning, we could spend years deciding what structures to base things on. I often think, and the articles I quoted by Mintzberg support this, that a lot of time can be spent

getting into structures, reorganisations, new logos and new this, that and the other, and this takes away from the energy of doing the work because at the end of the day, whatever the size of the population, people have to work together.

The new community health care organisations are a good starting point. It causes some amusement that community health care organisation area 4 looks a lot like the Southern Health Board of old, so we will kind of go back to the future. I would not get too caught up in that. They need to be sufficiently localised to connect with people. They should not be too remote. Within a community health care organisation, there could be clusters but the voice of the citizen has to be active and not just an afterthought. It should be driving them and having these kinds of conversations directly with commissioners and providers of organisations.

That is what the NHS Citizen project is about. It is about enabling the citizen, provider and commissioner to have these conversations. Very often when we have the citizen meeting the health provider, it is in a situation of frustration and anger. Those conversations are very understandable but they often do not go anywhere because the provider gets entrenched and hides away or the citizen is so cross they cannot bear to talk. It is not just the "what" of the planning forum but also how they operate. They need to be on a statutory basis. The homeless forums were great but they came and went. Does that answer the Chairman's question?

Chairman: Is the Senator talking about citizen representatives participating through service user groups or through elected public representatives?

Senator Colette Kelleher: I am talking about both and about any other methods we might need. One of the good things about the national dementia strategy is that there are people with dementia actively participating in it. We need to see that in all these forums because people are able to articulate their needs and indicate their preferences. There needs to be new ways of working in order that those kinds of different groups can converse with each other. It is equally an issue with the professions. For example, sometimes the physiotherapist does not talk to the occupational therapist about the care needs of the person. They need to do that. There should be all these different conversations but they should be driven, as Senator John Dolan said, by the needs of the person first and foremost. Things like personalised budgets shift power in a very meaningful way. It is something we need to look at seriously.

Deputy John Brassil: I thank the members of the Seanad Civil Engagement group for their presentations. This has been one of the craziest mornings we have had in the Houses of the Oireachtas. There are so many different people trying to meet. I welcome the individual presentations. I have one question which I will address to all three Senators if they wish to comment. In each of the Senators' area of expertise, do they see the issue as one of resource and financing or does it comprise organisational issues? Perhaps it is a combination of both. If there was enough finance and resources in the morning, do the Senators believe they could do what they need to? Does the organisation need to be totally changed for them to achieve their goals?

Senator Colette Kelleher: Unfortunately, it is both. The organisation and culture issues cannot be underestimated and neither can the inflexibility of the systems. Expenditure on social care services for people with disabilities is €1.5 billion but it is very tied up. If people say they want services delivered differently, it is extraordinarily difficult to do that in response to them. We might have the same amount of money we want to spend differently but it is extremely difficult because of the way the systems operate. There are shortfalls as well. If one looks at the annual report of Cork Simon Community, where I worked for eight years, it shows that it has to fund-raise half the money it needs every year to support 1,000 people in the city. There is a

funding shortfall there. Services and supports for people who are homeless in the city should not be reliant on the kindness of people. They should be on a stronger footing than that.

It is great when people are generous. I was very grateful when I was working in that organisation because it allowed us to do certain things. One of the things we did was walk-in counselling. Very often people with addictions could not access counsellors because they had to be sober. People were not going to become sober overnight, yet they had to make that leap. We innovated in that way with walk-in counselling. Someone might not be able to wait three weeks for an appointment. They might need to see a counsellor at the time. That is an example. It is an organisational and cultural issue but there are also big resourcing gaps.

Deputy John Brassil: That is very helpful.

Chairman: What is Senator Dolan's view on that?

Senator John Dolan: The Deputy referred to a combination of resourcing, financing and organisational issues. It is beyond that. I am not saying these are not issues, however. We are being wasteful by not coming at this from a different perspective. We keep talking about the cost of everything and we are rationing all the time. I accept cost is an issue but we have to get our heads - our spirits - into a place where we have two choices. We either let these people wither and die or we do what has to be done over a period to ensure they can participate fully in society. That means getting back to some things and opening another front on prevention and early intervention, while drawing people, families and their support groups into the work and getting a more genuine partnership.

Services have been sliced and diced and it is said this is the way they will be provided. That is more and more madness. Yes, people need a roof over their heads and they need people to help them in residential settings and to have activities. Why are we looking at day programmes as the standard and not asking why are these people not migrating into activities in the community, work and jobs or whatever? It needs to be approached that way and that one starts migrating from the dysfunctional approach we have.

To be a charity, the test is that one has to be regarded as a public benefit. All of the organisations that are part of the State are there because they are considered to be a public benefit. Now one has not got the State and the charities at two ends of the spectrum. What one has is a different governance. The HSE, Health Service Executive, is a creature of the State, as well as all the other public bodies. An organisation that sets itself up is a creature of the people who set it up. Article 40 of the Constitution gives people the right to set up organisations and unions. That is a basic democratic principle.

Recently, I was at some meetings with colleagues from Poland and Hungary who are quite concerned about the shrinking of the civil society space. That does not give licence to not being a good well-organised or well-governed entity, however. There are many smaller organisations which get little or modest funds from the State. They might be dealing with people with a particular condition, of which there may not be a significant number. They need to create a brand or public awareness around that condition to ensure people who get a diagnosis of that particular condition will come to them. They also need it to be able to raise funds and operate in the public sphere to create further awareness.

There are complexities around this. In the private sector, there is legislation to stop company amalgamations because they might not be good for competition. We need to look at this.

What about the idea of autonomy and choice? There has been a blossoming of smaller organisations around mental health, neurological issues, local groups and suicide prevention. There is a tension between the benefit of keeping it at a tidy number and the benefit of allowing 20 groups create a head of steam about a certain condition.

The Chairman said the charities area is quite a problematic one and there needs to be more cohesion and accountability. That could be said of the whole spectrum of State services, private businesses and voluntary organisations. I am in the Disability Federation, an umbrella organisation for 130 groups, some of which are very large and significant direct service providers. It might be like church-run schools where there is a time when an organisation goes from being on the edge and providing a service no one else is to becoming funded and core-supported. There is a time to relook at that.

For the other ones, it is more about how we can put in back offices and get them to work in tandem. Take three organisations dealing with children who have similar conditions. It would make sense that they would not all be trying to have someone in Cork and Kerry to visit the children they deal with.

We went down a road in the early noughties to deal with and improve governance in organisations. It was very hard to get any interest from the State. We only woke up to the idea of governance when the banks went wallop. Understandably, we have been very strongly on the side of compliance since. The other side of governance is the UN Convention on the Rights of Persons with Disabilities. That states all of Ireland has to dance to a particular tune to ensure people with disabilities can be included. This can become the hook for us to have hard conversations, not just with Departments but with organisations, that this is not just about the organisation or agency on its own anymore but that this must be moved on at a societal level. I am not going to defend poor and wrongful practices because they harm people with disabilities. I know that so well.

Chairman: Senator Colette Kelleher made an important distinction between advocacy groups and service providers. Too often in our past, charities have had to step in to provide services where the State has failed. We seriously need to look at the State providing services that it should have provided in the past and, in that way, to bring more coherence to service delivery as well.

Will Senator Frances Black comment on Deputy John Brassil's point about whether the main problem is organisation or resources?

Senator Frances Black: It is a bit of both. I feel very privileged to address the committee today. Both of my colleagues from Civil Engagement are very experienced in this area. I probably do not have the same experience. I can only talk about the experience I have had in the charity sector working with the RISE Foundation, which I set up myself, and the lack of resources we have had. We provide a service for family members who have a loved one with an alcohol, drug or gambling problem. Many of these families are in serious crisis with serious mental health issues, particularly partners, mothers, fathers who are suffering horrendously with anxiety and depression. When they come to the RISE Foundation, they are in absolute crisis. We have never received any funding from anybody. We have 50 people attending our service this week alone and all 50 of those service users are in absolute crisis. We have started to partner up with other organisations, such as the addiction service Turas in Dundalk, and the Family Support Network. We really believe in partnering with other organisations.

I can only talk about that experience and apologise if I am not answering the committee's questions. I can only speak about the lack of resources and how extremely passionate I am about being a voice for the families in question. I try to represent them as best I can. I really do want to work with the Health Service Executive. In fact, it is one of our goals to prove to the executive that we can provide a very good service and replicate the fantastic results we have seen in the evaluations we have done. I am not sure whether that answers the Deputy's question.

Chairman: Senator Black makes her point very well that the distinction within the HSE between mental health services and addiction services is an unreal distinction which needs to be bridged and that the services must be co-ordinated.

Deputy Pat Buckley: I thank the witnesses for their educational presentation. We all are here to learn. It seems clear to me that what is lacking in the system are empathy, education, support, equality and inclusion. Senator Black referred to dual diagnosis, which is a new development. Surely, in 2016, we should have got to the point where we know what is required in terms of empathy and education and the supports that should be in place. Unfortunately, the entire system is fractured. Senator Dolan observed that it is not all to do with the health service, that we must also look to social inclusion. It is about people getting out in the world and making approaches. Many people with disabilities are not sick. We must ensure they have the best quality of life we can provide by focusing on equality and inclusion. A simple step to implement would be the provision of streetscapes on all main streets, ensuring they are wheelchair accessible, there is the correct colour code and so on.

I agree with Senator Colette Kelleher that certain groups continue to be excluded. Again, this usually comes down to a lack of education. The Traveller community suffers a great deal in this regard. The extremely high suicide rates in that community are not being reported properly and many Traveller families have been let down. LGBT people have also suffered but, fortunately, through education and inclusion, people are getting their stories out.

Returning to Senator Black's point about dual diagnosis, it comes down to three factors, namely, education, empathy and support. Each person is an individual with specific needs and should be treated as such. There is always an underlying problem in these cases and it is vital to identify that problem as soon as possible instead of allowing it to fester until the person eventually presents for help. GPs have a vital role in this regard and we should be seeking to nip these issues in the bud at primary care level. The greatest problem in this area is that there does not seem to be a consensus on how to proceed. We remain a cure society when we should be a preventative society, even though we would likely spend three times less if we looked to prevent rather than cure.

I commend the witnesses on their contribution. We are all here to learn as we work to make improvements for the future.

Deputy Louise O'Reilly: Senator Dolan referenced Article 40, on the right to form associations. That article is the basis from which I made a good living and is an issue about which I feel very strongly. I would like to explore the journey from advocacy to service provision. I am not sure I share all the Senator's views on the role of the State in this regard but I recognise that there is a replication in the charities sector. Senator Dolan will correct me if I am wrong but it certainly seems to me, as an observer, that there is a problem of duplication to be addressed. Many of the criticisms of our health and social care services revolve around their silo nature whereby A does not talk to B, and B, in turn, does not talk to C. There are multiple charitable and voluntary organisations dealing in the same area. Without wanting to stymie their advo-

cacy function, which is incredibly important, I would like to know what scope there is for co-operation between charities.

Senator Colette Kelleher spoke about the limitations that are sometimes placed on service provision. Without meaning to put words in anybody's mouth, I wonder whether that is because of the mechanism for service level agreements. I suspect people are given a tenner and told to do €50 worth of work with it. Again, there are multiple agencies and a great deal of replication because the governance and administrative systems have to be in place. That can create a difficulty. It seems some charities suffered more than others in terms of cutbacks because they simply did not have a buffer. Smaller organisations, in particular, have felt that pinch considerably. I am interested to hear any observations the Senator might have in regard to service level agreements. It is the model that seems to be driving most provision.

I am aware of the good work Senator Black does in the area of dual diagnosis. The Government sector, including the HSE, is not doing enough - if it is doing anything - to address the issues in this regard. There must be a link-in with mental health services. I am interested to explore the extent to which there is a difficulty in this respect given there is largely no recognition of dual diagnosis despite the general acceptance that it is an important issue which needs to be dealt with. I am wondering about the extent to which charities can shape policy, including, but not solely, in respect of the issue of dual diagnosis. Or is the policy of charities mostly driven by the funding that is available to them?

Deputy Billy Kelleher: I apologise for missing the start of the meeting and thank the witnesses for their contributions. From a broader perspective, we are talking about trying to develop a health strategy for the country for the next ten years. That is the purpose of this committee. In that context, the role of the charities and advocacy sector and how it should fit into the broader model is an important issue for discussion. We all tend to look to the State to do everything in the area of health care provision but it is important to recognise the very important role for civic society in this regard and the need to encourage continued charitable giving. This can be done by giving of one's time, service and support or via donation. The charitable instinct is a noble attribute which we should encourage in our society. We must not, however, have a situation where society is totally dependent on charity, with the State abdicating its responsibility.

There is a large number of advocacy groups working, with varying levels of success, on particular campaigns and to raise awareness of specific illnesses and diseases. Some of these organisations move from advocacy to service provision, which is where things become more complex. In the area of counselling or disability, for example, how does one encourage as much effort as possible while also ensuring the service being provided gives the best clinical outcomes for individuals? There is a need for clarity on this question of the regulation of services.

Another important question is how we can build the work of charities into the primary care sector. I do not wish to pre-empt the work of the committee but primary care is certainly viewed by most people and most expert groups and organisations as the way to deliver health care in the years ahead so that we keep chronic illness out of hospitals and deal with most things in the primary care setting. How can we complement charities working with primary care and broader community services? Meals on Wheels is an example. It is a very simple concept but it is a very important issue in Ireland where people give of their time to give meals to people who need them. It is more than just the nutritional value; it is the contact. The issue concerns complementing or supplementing that with home help hours with the public health nurse feeding in. Where do the witnesses see the charitable sector fitting with State services in a co-ordinated

way that does not stymie individuals who want to set up charities or advocacy groups? Where do the witnesses see that sitting in terms of trying to deliver a health strategy?

Chairman: There are a number of related questions.

Senator Colette Kelleher: The local health forums suggested in my submission are a way into that. As well as the commissioners, which are the HSE, and citizens, one has the organisations that are concerned or involved. They could be advocacy or service delivery organisations and sometimes they are both. The Cork city homeless forum was a brilliant example of that in the noughties. The HSE, Cork City Council and the organisations sat around the table and planned very coherent services. One group was missing, namely, homeless people, and that would need to be corrected. By 2011, there were enough beds for everybody sleeping rough in the city so the forum was very effective. It was not on a statutory basis so it could come and go.

Those kinds of planning forums involve people working together at a local level. The Carlow-Kilkenny model is good, except that one does not find the patients or the charities in there working together. Each has different roles to play and everything does not have to be done by professionals, as sometimes a volunteer can be involved. If someone is living in a residential setting and fancies going to a match on a Sunday, he or she does not need someone with a nursing qualification to do that. It involves those kinds of groups working together, while being driven by the person and citizen rather than the vested interest of, for example, the charity that has always done this work in this way or the professional who must leave a shift at 8 p.m. so everybody has to go to bed at 7 p.m. It is about turning the planning and delivery of services on its head so that it is focused on what the person needs.

All the different actors need to play their part. If charities serve the citizen in advocacy or in providing services, support or volunteerism, they have a role to play and if they do not, they do not have a role. The restrictive practices piece does not just relate to charities. It relates to shift working and working in different ways so that it meets the needs of the person. It is not just about the "stuck-ness" of the system we have. Practices cut across the different interest groups. The professions and charities are in there with their stake but those stakes have to serve the person. There is a unique opportunity to turn things on their head.

The service-level agreements mentioned by Deputy O'Reilly are very rigid and restrictive. There is no doubt that, most of the time, organisations with them deliver more than they are paid to do. There also is an opportunity to look at those in terms of expecting good governance and public accountability from the charities. I am interested in the debate about the national maternity hospital and the arguments between two different groups. Service-level agreements are ways those groups could be forced into because at the end of the day, it is for the State. However, the State often underfunds those agreements.

Regardless of whether it involves a provider, a commissioner or a person working on the front line, unless empathy is at the heart of all this and we do what we do kindly and properly and do not get disassociated from the person at the centre of all of this, none of it matters. That point was very well made by Deputy Buckley.

Chairman: A number of members raised the issue of dual diagnosis.

Senator Frances Black: I am very concerned about this area because we are aware of the relationship between alcohol, drugs and even gambling and mental health and how they are so closely linked. Gambling probably has the highest rate of suicide out of all the addictions.

When I worked as a therapist in the Rutland Centre, I do not think I had met anybody in there with an addiction who did not have underlying issues with mental health, depression, anxiety and stress. My concern is they are not really under the umbrella of mental health, which plays such a huge role. I know a new youth task force has been set up by the Minister of State, Deputy McEntee, and it is a fantastic idea. However, my concern is that nobody on that task force is talking about dual diagnosis or the role of alcohol, drugs or gambling and young people. I know that gambling in particular has gone off the Richter scale because there is such easy access to it on the Internet. From a mental health and addiction point of view, people need to work together. The issue needs to be addressed.

The services around addiction are atrocious. There are no services specifically for alcohol on the west coast, which is shocking. Again, I return to the fact that three people a day die from an alcohol-related illness. I agree with Senator Kelleher about round-table discussions, meetings involving all of the services and, in particular, about the importance of being citizen-driven. It is vital.

Chairman: I would be interested in hearing Senator Dolan's views about the issue of the delivery of services through the primary and community care model and the role of charities.

Senator John Dolan: I said earlier that charities are allowed to be charities or are granted that status because they have a public benefit remit. I keep seeing that as the thing that can help us to be more coherent about where and how they fit. A lot of these organisations set up and got into provision by default because they decided to roll up their sleeves and do something. This is not to blame anyone. It is a case of people saying there does not seem to be a door they have knocked on that has the answer for them, so they will get going on it.

From my experience across the broad sector, I get caught up in definitions. Is giving somebody support, advice or contact information a service? I think it is but often when we talk about services, we are actually talking about the hard services and very often the ones that cost the State a lot of money to provide. There is a continuum. In terms of advocacy, support, a place to first listen to somebody and say "this will be all right. Others have got through this and survived", many organisations are very poor at understanding and articulating those things they do. They have got caught up in the idea that if they cannot say they are providing a service, they cannot get money. There is much dysfunction. Let us be very practical and see what the State can and ought to do best, or what can it do with certain arrangements, contracts, etc.

We should remember there is a third ring in the circus. We speak about the charities and the State but the private sector is involved with this as well, regardless of what some of us might or might not think about it. That is becoming a bigger area. We must figure out in a practical sense what can best be done by an organisation that is generally close to people and which people have an affinity for, and which can be flexible in its responses and stand up for a group. That is important. How do we ensure such an organisation would provide very hard services around the clock? I do not know if that helps in some way. There is a continuum between the private and public entities. There are different ways for the State to ensure the services, as it can carry them out or make arrangements for them. The section 38 and 39 groups add to the confusion in this as well.

May I address some of the other issues?

Chairman: If you are brief, as we have been sitting since 9 a.m. and are keen to wrap up very soon.

Senator John Dolan: Some of us are the fresh legs for the second half and did not appreciate that fact. Senator Buckley mentioned some health services that are at the core. This health issue must eyeball other parts of Ireland's public service. The education of kids is the education of all kids, employment is for all and public transport and income supports are for all. The health sector must get its mojo going and stop being on the back foot all the time. The Health Service Executive could start to warehouse people for the rest of their lives or instead other Departments and entities could get a move on in considering how to get involved. That is whether people are involved full-time, part-time, in jobs or community activities etc. That relates to the prevention aspect mentioned by Deputy Buckley. We can stop, slow down and ameliorate things but it is about where a person has mojo or whatever, with confidence built up. That often happens by seeing other people who have gone through the process or where families have capacity. If a family has capacity, whether there are one or two parents, regardless of issue, the doctor or voluntary and State organisations do not get put under pressure. There must be capacity in families and support entities, particularly smaller groups of all kinds. They can be bedraggled in how they operate. They are often who gets called and who offers invisible support.

Deputy O'Reilly referred to co-operation and co-ordination. In a sense I have exercised that a bit in some of the comments. There is genuinely territory that we have not explored at all. We might have different views about it at the end of the day but there is a whole area of the pitch we have not gone near in solving this.

Chairman: I acknowledge the submission made by the Disability Federation of Ireland. It is very comprehensive and we very much appreciate it. A number of members of the committee were not able to be here this morning because the meeting clashes with other committees. That is an issue we are all grappling with. It is very unsatisfactory and the issue must be dealt with separately. I thank the delegation for coming along this morning, giving a very full presentation and answering our questions. We very much appreciate the input to the committee. That will certainly be reflected in our final report.

The committee adjourned at 12.25 p.m. until 9 a.m. on Wednesday, 12 October 2016.