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RI World Congress
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Parallel C Moorfoot
Delivering practical community based solutions

Sean Williams: We've got a couple minutes. Its 1:30, but we'll wait for any stragglers after lunch. We'll make a start. Welcome to the afternoon session. Thank you very much for attending. I think it will be an interesting session. We've got some fantastic speakers. The topic is delivering practical community-based solutions. As I said, we have four presentations. They will take 10 to 15 minutes. That will give us questions at the end. I'm delighted to welcome Joshua and Simmone. They are talking about decision services in England.

Josh Feehan: It's about raising the standards of vision across England. I work for Royal National Institute of Blind People. At the age of 15 I was fully sighted and over a period of a month I lost the majority of my sight. I only have 20 percent vision in both sides. I'm classed as registered blind. It was quite a traumatic and difficult time for me and my family. One thing that really would have helped is able to access vision rehabilitation services. We will describe why that is so important. With me today is...

Simmone Miller: I have a different type of issue related to sight. In my 30s I already have myopia. It's short sightedness. Can I ask for a raise of hands? It's people in the back. I don't know what that means. You should be at the front. [Laughter] I would assume your prescription is like mine, one or two. Mine is minus 20. That gives you an idea of how survive my sight is. At the moment I have a cataract in one of my eyes. I'm describing a different type of sight lost which is generally for people who are getting older. I'm experiencing a different type of sight loss. Before I came to work for RNIB I work as a [inaudible] worker. Part of my role was I became a manager and managed vision rehabilitation services at a local council. We will talk about vision rehabilitation. Myself and Josh have different experience of sight loss. Hopefully this will be relevant to you on lots of different levels.

Josh Feehan: Sight loss in the UK. There are over two million people living with sight loss across the UK. A lot of sight conditions are age related. There's a higher level of sight loss for older people. 20% of those over the age of 75 are affected by sight loss. Half of the age of 90 are living with some form of sight loss.

Simmone Miller: Our priorities are tackling these issues. We are the largest charity supporting blind people.

Priority one is helping people rebuild their life. The second is about independence which is crucial if you experience sight loss. This is about being able to maintain your independence or regain it if you have lost it. The third priority is about inclusion. As many people with disabilities will tell you, we need to include people that are blind and partially sighted people as well as all disabilities. We want people to be equal citizens as citizens of [inaudible] to be able to access different products and services. RNIB realise that there are lots of reasons that people lose their sight and that could be avoided. Making people take responsibility for their eye health.

Josh Feehan: Just to give you some examples of some of the work we do at RNIB, we tackle issues that blind and partially sighted people face and sight loss that can be prevented. The first one we do partnership work and our most recent partnership is a three year partnership with speck saver optician. That is around people looking after their eyes. It's very important piece of your body that people don't look after. Secondly, RNIB connect. As you can imagine, when people lose their sight what is key is support and people who have been through similar experiences. RNIB we have over 28,000 members who interact and provide that emotional support at a peer level. Thirdly, we are primarily a campaign organization. We want to tackle issues faced by blind and partially sighted people. Some of those issues might be employment issues, health and social care, welfare rights, benefits and also public transport is a key issue for people with sight loss. These are tackled at local and national levels. We regular meet with central government to tackle these issues. One of our key [inaudible] is the sight loss advisor. They are in the hospitals and clinics. This is an important role that we promote and we provide training for this profession. They are there when someone loses their sight and given the diagnosis of losing their sight. This person gives them support right away and help them with services they may need. Another fantastic thing that we do at RNIB is we make our talking book service free of charge. There are thousands of titles that people can access completely free of charge. Thank you.

Simonne Miller: The purpose of our presentation is to explain what vision rehabilitation is because I do believe that people are not aware of what it is. I only came across it because I happen to work in the field. Had I not worked in rehab work, I would not have known what was available. I'm going to talk about what a rehabilitation worker does so you may apply from where you live whether this is a role you should be thinking about for the people you may be supporting. I'm going to talk about the importance of raising awareness of vision rehabilitation and the benefits from the point of view of blind and partially sighted people. What is the benefit of these services? Why come all the way from England? I want to share with you what good practice should look like. Even if you're thinking about whether it's important, how do you know if it's good? We're going to help you with that. Lastly, I would like you to think about and consider the vital role of vision rehabilitation as I explained and whether it's something you can apply to where you live. So, what is vision rehabilitation? Can I have a brief raise of hands if you know what it is about? One hand?

This is great actually. It means I'm not going to be talking about things you already know and I have an expert in the back.

So, I broken it down to a few points to break it down to what it is. It's a crucial part of the sight loss journey. Not many people know -- it does apply to Scotland but if the ophthalmologist says your sight loss is there's nothing else we can do with you, someone would be certified to be blind or partially sighted. That document is like a legal document. It gets sent to the local authority. It would go to London council if I lived there. This legal document is details of what the sight loss problems are. Then it gets sent to the local authority or council and it would be picked up by a sensory advisory team. When I used to do that job I would get these forms all the time. They were devastated being told there's nothing more to treat their sight loss. It's a massive devastating piece of information to receive. Once that person receives that, then the rehabilitation worker would give them a telephone call and hopefully within a certain period of time explain there is help and we will come out to see you which is what I used to do. A rehabilitation worker, this is based on supporting someone who has lost their sight, whether partially or totally. We work with any grade of sight loss. If someone wasn't certified, a worker would still work with that person. So if might be a family member saying my grandmother has gone blind. Can you add support? The vision rehabilitation worker is specially trained to provide specific training advice to support a blind or partially sighted person to look at what risk to identify and manage the risks. It's about asking that person what are the things they're most afraid of. What are the things they can no longer do at all? When I worked in the job, lots of people couldn't go outside anymore. So how can I impart the person with the skills and confidence to do those things again? Four main areas that we do as a rehab worker is to support someone to have the confidence to live more safely and independently at home. If you lived in your own home, you imagine you should be fine. We have people that have problems in the kitchen. Preparing a cup of tea. How difficult that can suddenly become. Preparing your meals. I like to do a Sunday roast or a meal in the week, those are the things that people I worked with used to find difficult. How do I peel my vegetables or chop an onion or the day-to-day practical things. A rehab worker would help that person to see if that's a difficulty they want to overcome. Traveling independently is a huge one. This is getting to and from places. Going to your church or GP surgery. If you lost your sight -- I experienced that personally. Where do I need to go and can I get a taxi. A rehab worker will say do you know how to use a white cane. I brought a long cane. Those in the back that are short sighted may not be able to see this. This is one of many pieces of equipment -- I will demonstrate later if anyone is interested -- to help people get from A to B. This long cane has a grip handle, a ball on the end and it's got a length that would cover shoulder to shoulder to get around. We would teach somebody having no skills to actually be able to master something like this. That's one of the tiny things as a rehab worker would do. It's not just about using a long cane like this. It's quite cumbersome. Some people may not need that level of support. Coming to a conference I may need a guide cane. That tells

other people that person has a visual impairment. We teach people how to manage things like that. That's a life-changing thing to get used to having to use a cane.

One of the other areas that a rehab worker would help somebody support is using technology. A lot of us are dependent on using our mobile phones. Imagine if you lost your sight overnight. That piece of equipment that you used to text people or e-mail people is something that's quite difficult to access. A rehab worker like what I use today do, we might put a marker on that phone, and we might help someone use speech on their telephone. We've been looking for different solutions the person may have. I have remain employment. Unfortunately, the employment rates are low. We would be looking at ways to help people stay in employment. I use today work with people that have said I have given up my job. We would say don't hand your notice in. For many people it may be using the long cane. It might be that they need to go on a user guide dog. To do that, they have to have skills to use a long cane. They have to learn four different routes. It might be to the GP to the church to the doctor to the local shops. They have to be confident to use a cane before they go on to a guide dog. Guide dogs don't just appear and off they go. You have to be mobile and show that you can manage if the guide dog is ill. Using the long cane is crucially important and that's exactly what a rehab worker would give someone the skills to do.

Sean Williams: Four minutes.

Josh Feehan: What is the needs? I will go quickly. What is the need to sustainable vision rehabilitation? There is increase of demand and not enough resources to deliver them. That may not surprise you. The [inaudible] increase in statistics. 2% increase over 12 months. 1.3 million more appointments across the country. Our own research demonstrate that there is only one in 5 that access support. 46% of people were referred on to vision rehabilitation services which is a worry. There's a reduction in rehabilitation services over the past 3 years which is really a big issue. Again, there is a decrease in the work force across the last 5 years. Again, reason to be concerned. So what are we going to do about this? As an organization, we want to make sure there isn't just issues in terms of the provision & there but the quality of the provision. We took it upon ourselves to develop good guidance. We built on existing governance. We use some research [inaudible] over thousand blind people have said this is important to them. Adult social services in England. Also research done by York University. We have done consultation with over 130 professionals and blind and partially sighted people. Now we have the document. Who is it for? We have copies you can take away. What they cover, every part of the journey from the initial contact to the assessment to the rehab training. We describe what good looks like for each of those stages and break it down. I will give you a flavor in a minute. Just finally, you can find the principles at RNIB.

Simmons Miller: The telephone contact that I mentioned, the assessment I mentioned, the person should offer a range of services. The fourth is about a plan giving to that person within 28 days. The fifth principle is about offering services free of charge. Sixth is [inaudible] it isn't suitable if they are unable to do some of

things we described. Seventh is equipment. 8th is receiving information in accessible format. Ninth is about services offered in the future. The 10th one is about people delivering rehab having the right skills to do so.

Josh Feehan: Thank you. We haven't finished yet. So just to say this is a wider program of work. The department of health recognise there isn't enough evidence out there around vision rehabilitation. What we are trying to do are three objectives: Raising the standard of vision rehabilitation around England. Making sure the professionals are aware of what rehab is and the benefits it provides. We want to empower blind and partially sighted people to know what vision rehabilitation is. Some other pieces of work we're doing is a cost benefit study. The cost benefits for the public sector around what vision rehabilitation provides. Finally we'll move on to our vision finally, our last slide. What we want to happen in the future: We want service providers to utilise the principles that the services are in line with the 10 principles. We want all blind and partially sighted people to be aware of vision rehabilitation and accessing it and getting the benefits from vision rehabilitation. Finally, thank you very much and there are links there to the principles.

Simone Miller: We have booklets in the back. Thank you.

Sean Williams: Thank you. [Applause] I failed my first duty as a moderator keeping to time. It was just a fascinating presentation. We're going to go to demographic solutions with welfare technologies at Vikaergaarden Aarhus. Welcome to Inger, Lotte and Monica. Apologise for my accent.

[Muffled mic].

Female Speaker: Thank you. We would like to start by saying we're happy to be here and honored. This is going to be a little appetiser for the RI World Congress 2020. We want to give you a practice base presentation. The three of us represent an interdisciplinary team in Denmark. We work at integration of rehabilitating patients.

Female Speaker: We hope you will be given an insight on how patients benefit.

Female Speaker: We are facing a demographical challenge. In Denmark the number of persons 65 years [inaudible]. There will be 1.5 million people in this age group. There will not be the same number of persons in the working age and nor will the budgets be increased. There has to be focus and new ways to continue a good and professional health care system despite of the demographical development. One of the ways the city of Aarhus is by implemented welfare technologies that makes it possible for the citizens to get more rehabilitation and stay longer in their own home with minimum health care.

Female Speaker: In Denmark we have medical and rehabilitation unit and at the same time it's a center for testing and evaluation. We work with the patient being at the center of the team. The team consists of a nurse and an occupational therapist and physiotherapist. We work together 24 hours a day to help the patient reach their goal. They are granted rehabilitation [inaudible]. They will stay 2 to 5 weeks. They will

have their own room that is equipped with different technology. The patient must have had a recent loss of function. The patients are 18 years and up. The majority are 6 to 5 and upwards. It is free of charge or paid by the taxpayer's money.

Female Speaker: Center for testing and evaluation is established as Vikaergaarden. To test welfare technology and practice among patients, level of function and age. The three of us imply at the center half time. The other half time we work at practice at Vikaergaarden. You probably all met a sales person that says he has the best product on the market. We have to test it. Center for testing and evaluation gives us the opportunity to test and evaluate technologies to find out if one is better in a specific situation than another. The results we get we give to the companies that are develop the welfare technologies. With this they develop even more on their product. System tests and evaluation of the welfare technologies makes it possible for the decision makers in Vikaergaarden which technologies to offer to the staff and citizens Aarhus.

Female Speaker: Please, meet Jensen. She arrived. She had a long complicate /-TD stay at the hospital. Two months earlier, Mrs. Jensen had a stroke. Additionally, she had cardiac arrest resulted with her being omitted into intensive care unit. She was using a wheelchair but able to stand for short periods. Before the stroke she was living in her on apartment on the first floor. The investigation of the patient starts on arrival. The interdisciplinary team meets the patient at the door and sets goals. Mrs. Jensen's goal is to go back to her own apartment with help from the home care system.

Female Speaker: A good night sleep has a great help on the rehabilitation. She claim today sleep worse than she did before. With one of our technologies we have a good insight on how relax she is while lying in bed. We see if she is turning enough. After a few days we had a clear impression of how interrupted Mrs. Jensen's sleep was from the micro activity in the muscles she was very tense throughout the night and only lying in bed for a few hours. The interdisciplinary team and Mrs. Jensen discovered through dialogue a possible reason for this bad sleeping quality. With this information, the staff had a better condition for communication with the doctor about what the reason was for Mrs. Jensen's sleeping problems. After medical treatment, Mrs. Jensen had slept all night. Before these kinds of technologies we didn't have access to how the patient slept at night. It lifted the quality of our investigation. Mrs. Jensen ended her treatment. The doctors are aware that she is still vulnerable and want to follow her a few more days. We don't have doctors in the house. They are connected to their own doctor or a team from the hospital. The doctor from the hospital who knows Mrs. Jensen sees her through this. The doctor sits in her own office at the hospital and connected through a computer program controls a robot to Mrs. Jensen. These consultations are assisted by a nurse from the house.

Female Speaker: It is difficult for Mrs. Jensen to go to the toilet by herself. She can't clean herself. It is a private thing for her. It's important for her culture of life that she can go and has the control to go to the

toilet immediately and independently. To make this possible for Mrs. Jensen, we have introduced her to wash and dry toilet. Mrs. Jensen has previously had several urinal infections. The toilet cleans her. [Inaudible] there are a huge benefit for the staff. The wash and dry toilet helps the staff with the cleaning. With this they don't have to work in a [inaudible] position. A wash and dry toilet is one of the welfare technologies the citizens can get for free in their own home if it makes them independent at the toilet or if they have had several urinal infections.

Female Speaker: At Vikaergaarden, we have the opportunity to start physical training such as stand function training much earlier than physio centers. Mrs. Jensen involves her standing function with this machine. At the time [inaudible] at the knees and ankles. We have a game stimulate a shooting game which is on a screen in front of her supporting her movements.

Female Speaker: This makes training more motivating and fun.

Female Speaker: Training on the stairs can be dangerous. There is an increased risk of the patient falling which can cause injury to the patient and the physiotherapist. Technologies allow us to train at the stairs earlier than traditional training. The staircase can lift up and down making it possible to adjust the height of the steps like the ones at the patient's home. The sling together with the ceiling host system makes this safe for both parties.

This functional training is extremely advantage for the patient.

Female Speaker: It is important that we get Mrs. Jensen's and the staff evaluation of the welfare technologies that she has used during her stay at Vikaergaarden. To get this data we use an electronic evaluation tool. It's a dialogue evaluation with the patient. Together with Mrs. Jensen, we go through a 10 questions about how the welfare technologies have worked for her during her stay. With the data from the evaluation, the companies who have developed the welfare technologies can get the results about how their welfare technologies. It gives them the opportunity to develop more on their product. With about 700 patients through Vikaergaarden a year, this evaluation gives data to the decision makers. An evaluation takes about 10 minutes. We can use any iOS or tablet.

Female Speaker: Mrs. Jensen regained enough strength to go back to her own apartment with minimal help. Only 5 weeks ago after having had a stroke. Within a few weeks she managed to get to a functional level where now she can leave only using a traditional walker.

Female Speaker: She is free of infections. We have arranged she got a wash and dry toilet. She lives with a happy smile and a good experience about how welfare technologies were an important part of her rehabilitation process.

Female Speaker: Our experience as health professionals are that we only achieve these successful examples if the technologies are tested, evaluated. It is not a simple thing to do. We get wiser all the time. We love what we do. The success make it worth it. We look forward to seeing you in Vikaergaarden in Aarhus

Denmark in 2020. Thank you. [Applause].

Sean Williams: Thank you for that. We are going to move on to Kathrin Schmidt.

Kathrin Schmidt: I have the task to take you back to theory because I'm going to be present to you the project through our research which is about developing a modularised curriculum. [Inaudible]. There are interlinkages between academia and practice. I hope to make a contribution to this session. Before introducing the research to you, I would like to have a look at the title of this conference and discuss how the project of our research is linked. The title of this RI World Congress is create a more inclusive world. There are two main agendas in my mind. The convention on the rights of persons with disabilities and [inaudible]. I think that I do not have to elaborate on the UNCRPD. You are aware of the UN and we are aware that the UNCRPD is linked to the idea of an inclusive world. [Inaudible] aims to guide global development until 2030. They had a specific [inaudible] and did not explicitly mention including persons with disabilities in the development agenda. The United Nations highlight the inclusive care of the sustainable goals. Many of the [inaudible] at the United Nations convention in the sustainable framework [inaudible]. It can be linked to sustainable and inclusive development. To ensure that people with disabilities are adequately considered in the process of implementation, it is necessary to apply different strategies. Not only is it crucial to convince politicians to include people with disabilities in development processes, it is timely to mainstream the topic of inclusive development into different study programs to ensure that professionals are able to think inclusively. This is the main objective of our research. So the main objective of the project research is to include the topic of disability into programs in order to raise awareness among today's students since they will be our researchers and developers. On this page there is a range of disciplines. You see an architect on the left. He should know about how to design new buildings. You see people participating in sports event. They should make sure that the activities they offer are inclusive. Lawyers should be aware of people with disabilities and their rights. They should deliver information in a way that is understood by all people. They should know how they promote information about a certain disability. Medical professionals should be aware of the needs of people with disabilities but they should attempt to reduce barriers to accessing medical care. It should be a given for teachers to adequately support children with diverse needs. You see a teacher using a wheelchair on the right side. We want to highlight that people with disabilities should also be among today's students and tomorrow's leaders and change makers although this is not a specific focus.

The CBR project wants to mainstream the topic of inclusion. CBR is being carried out between Kenya and Germany. In the course of four years we have been developing studied modules on inclusive development. We start the project that is supported by the German academic exchange [inaudible] and development in April 2013 and will have to close it at the end of this year.

The main aims of CBR research are the following: To build capacity in strengthening corporation and

teaching and research and participation and inclusive development. To build local human resources and scientific knowledge. To exchange ideas. To develop local solutions to make development inclusive. The partnership between Kenya and German university is linked to the United Nations convention and article 32 which highlights the importance of technical knowledge as an important step of inclusion of people with disabilities. To develop the study modules, the CBR research uses communication-based [inaudible]. I want to briefly introduce CBR to you. CBR was initiated in the mid-1980s to enhance people with disabilities and their families to meet their needs and ensure participation in low and middle income countries. CBR had a strong medical focus. Today CBR's conceptualised strategy to improve the equalization of social inclusion of people with disabilities while [inaudible] the cycle of poverty and disability. Based on this general conceptualization, CBR has two main objects. First to ensure that people with disabilities are able to maximize their physical abilities. To access opportunities and to be active contributors through the community and society. Secondly, [inaudible] to promote and protect the human rights of people with disabilities through changes within the community; for example, removing barriers to participation. CBR pursues these two main objects. It aims at providing individual and specialised services to people with disabilities, as well as mainstreaming disability to general community development.

Today CBR is promoted a strategy to the United Nations Convention to make inclusion. CBR has evolved from strategy for rehabilitation for some to a strategy for all. [Inaudible]. Health, education, livelihood, and empowerment. Since the CBR research had to cope with limited time frame we focus on three components when developing our study modules: Education, livelihood and [inaudible]. Looking at the structure we look at the basic module on participation in communication in 2013. Following the development of the basic module, we focused on in-depth modules. The module on disability and education was in 2014. Currently we're working on module on empowerment and disabilities. Students from Kenya and Germany have tested the modules in workshops and they use an online platform to develop review and update the content. From our perspective it would make sense to complement existing research modules and develop academic modules on health, participation and accessibility which is one of the cross-cutting principles in inclusive development. Currently we're trying to identify sources of funding that would allow us to work on these additional topics.

We look at community-based rehabilitation from a multidisciplinary perspective. We want to strengthen research cooperation and inclusive development.

So no matter whether we're able to continue working on the study modules or not, we are glad that we developed four modules and to test them with Kenyan and German students. One of the things we have learned is it is possible to raise awareness among students of different disciplines. Many of the students and those who don't have medical social science background can relate to the topic and see how their future work is linked to it no matter if they are from computer science or economy. To mainstream

inclusion would require lobby work within university and academia. All of the colleagues involved on the development of the study modules are working on the development of the study modules to their regular tasks. Time was always a challenge for us. This is one of the reasons we're still finalizing the modules. Without the support of these colleagues, we would never have come so far. All of these joint efforts will be celebrated in the closing conference of the project. I would like to take this chance to invite those of you who are interested in the research to attend this conference.

So the CBR research project closing conference is disability and the global 2030 agenda of sustainable development, can CBR serve as an inclusive development. It will be in Kenya from November 28-30 this year. If you have any questions on the conference, contact the team. You can approach me after the session as well. Thank you for your attention. [Applause].

Sean Williams: We're going to move on. Next is the analysis of the needs of the disabled residents in rural areas.

Jonghwa Jeong: Good morning. I'm glad to meet you. My title is analysis for the needs of the disabled residence of South Korea. I was a researcher in 2015. Introduction. I would like to introduce research as I show in the PPT. The Korean nationwide survey. [Inaudible]. This survey was beginning and a total of 9 times. Disability prevalence of rural households is 21.69 percent among 5%. The rural disability is 15.5%. Particularly in disability survey of 2014, 2.7 million are the total disabilities. This propose survey and first reflect of the situation of the rural disability that was not receiving [inaudible]. Second, providing basic data for setting the direction of disability welfare policy over the disabled. Lastly, contributing to disability research of the Korean disability [inaudible]. Research methods. Research propose survey contents. Particular as I did research I thought that we need to hear the participation of disabled persons. This is very famous. 100 people with disabilities discussion forum. [Inaudible]. There's a diagram piece. This framework FGI and town meeting and community living office. This map is of Yangpyeong population. [Inaudible]. This is the population and the community in Yangpyeong this PPT, look at the Yangpyeong population and table 1. There are about 1 million and 9 years later --. This map shows a rate of Korean aging as you can see. Most of [inaudible] are 10 percent. [Inaudible] as you see, preparation of more than 90 years old of 27.28% in 2040. The rural area population is very serious. Now let me introduce the survey. As you see this chart, the population of 15 years old is more than 50%. The population are growing. The disability and physical aging [inaudible]. Next is income. 100 million won and 730 GBP, pound. Korean disabled 100 million won is 20%. 150%. Okay, next graph. Conclusion recommendation. I would like to say the conclusion of this research and finish this presentation. Going to the rural area is very serious. There are developments of comprehensive [inaudible]. Welfare service consideration of the disabled aging. There are development of transit facilities, construction of the road, installation of elevator and low-floor bus and using the sports facilities of the disabled and the old.

Finally, I propose the result of this research. First I propose installing and operation of the integration information call for the disabled, tentatively named OK Dial. I proposed the meeting of a [inaudible] and medical service. This proposal was in Yangpyeong gun disability hospital to improve the level of the disabled medical service in rural rehabilitation. They have an interaction-based remote for the disabled. In particular, as you see the research here. [Inaudible] for progression of the disease.

Okay. [Inaudible] explaining access of long distance area for the employment of disabled. Finally, I proposed to provide the disable parents peer counseling in rural areas.

Okay. In the future, the disabled welfare can [inaudible]. They have to provide the basic data of disability. [Inaudible] justification and conduct a survey. Disabled welfare or employment and article 31 of disabled welfare law.

Time over. This is my presentation. Thank you so much. Thank you.

[Applause].

Sean Williams: Thank you very much. Our final presentation we have Claire Turnbull from the transition team from Scotland talking about the need for choice within communities to promote opportunities.

Claire Turnbull: I'll make it quick. I know everyone wants to head off and have coffee. CHAS, the organization I work for, anyone of you heard of it? CHAS stands for Children's Hospice Association Scotland. We're the only provider of children's hospice care in Scotland from 0 to 21. We currently manage a team called the transition team within the hospice. We have funded to run a 3 year program to support young people to leave our hospice and go to alternative care. We found that about 3 or 4 years ago 1 and 3 that were over the age of 18. They are living into their 20s, 30s and 40s which is great. But that meant that we have a 36-year-old that is next to a baby. They should not be receiving children's services. I would have a look at some of our initial findings and some of our feelings about autonomy and aspiration and dreaming. How do we move from the concept of there's nothing out there? How do we support young people to have a dream to aspire to something else? How do we move them to communities that should be resourced in a way that they can respond to the needs of these young people with life shortening conditions? They are a growing number in Scotland.

Just to consider the emotion of autonomy and being able to think of what it means to make your own choices in your life. The majority of the young people rely heavily on assistance from others. Wiping their tears away, scratching their nose. How do we support those young people to be independent and still exist within that parameter of independence and be able to make their own choices? The majority can make choices but how do we support them to do that in an effective way? We're a small team but we cover all of Scotland. Our workers work hard in supporting increase autonomy in our young people. We want to make their voices heard in every aspect of their life. Care and support what color socks they wear. You will be surprised how many 30-year-old men their mother chooses for them.

It's funny how dry you get up here.

It's important why we dream, what we should dream. We find that a lot of young people that because they thought they wouldn't be here they stopped aspiring to anything other than being stuck in their homes.

They live for the day but for medical treatment and not next week I will go on a holiday. Rightly and wrongly parents have done that too. How do we support young people to think about a future? They have a shortened life expectancy. Young people that we come across have forgotten to think ahead. The young people we work with will work on a plan. Some people it will be about getting a therapy dog and getting an independent [inaudible]. Some people it will be a break away from my family. For others it will be getting a relationship. Every individual has a different plan. The focus is on the here and now absolutely. It's given that their time is limited but it's more about thinking further ahead and what you may want.

We did a movie which I didn't think I would have enough time to show you. Probably being last I don't. We interviewed three young men with different disabilities. What they wanted wasn't anything different than what everybody else wanted. Make money, have their own business, get a girlfriend. They weren't anything different than anybody else.

The young people that we support have life shortening or life threatening conditions. They need palliative care. I've only been in this job for a couple years. I hadn't thought about the implications on the young people on their lives in terms of they have a unique sense of experiences. The young people that we support, [inaudible] have a muscular dystrophy and are wheelchair dependent and ventilated. They need a huge amount of support. They all have cognitive abilities and can make choices. Their life is very -- their health is very precarious. Everything fluctuates. They spend weeks in the hospital. They will have an infection treated. They can't get out of the house for weeks. So their health does dictate everything about them. I think services need to learn how to respond more effectively to that. Rather than if you have so many absences in school then you can't get in.

They have a life shortening condition. They are wrapped in a bubble by parents and protected but because of that they haven't been able to mature. We have 30-year-old men that don't pick their own clothes. He does drive and have a job. I think they don't have skills to move on. We're coming to them and say what do you want? I want my own house. Okay. They don't know what that means. At home they're a child, rightly or wrongly. They don't read their own mail or answer the door. It reduces their ability to think aspirational. They have suffered more loss than their peers may have. Someone 18 doesn't generally lose their friends. We support 85 young people in the project. The majority are 18-25. This year we lost two people within 24 hours. And the impact on the peers was significant. Not only are they facing their own mortality but having to deal with losing friends. One young man said I've never been to two funerals in 24 hours. [Inaudible]. I've never lost a close friend, let alone two in 24 hours. That is a huge impact on their emotional wellbeing. We do a lot of grief work.

I'm used to having more slides than 3 or 4. Social isolation, a lot of young people can't get out of the door. Otherwise they don't have the help or they have huge chairs or they're terrified to come out. The impact of that on their social life got reduced to peers, friendships. No opportunities to meet a girl and start dating. They spend less time with their peers and far more time with adults and children. So that impacts your development and wellbeing and confidence and one of the most common things that our young people that we support says I don't have the confidence. So a lot of what we do is very, very small. Baby steps. It does help people's confidence to get them out and about and hope will lead to the bigger picture. The other thing to consider is the physical barriers. Scotland is not the most accessible of countries. Physically getting from one place to another or accessing the community -- the community center may be 50 miles away. There are physical barriers along with the health barriers. Some of the young people have stopped going out and stopped doing things on their own. I had a young man that said he lives on the island. He can't get off. He said its fine. Everybody brings the gossip to him. His life exists in the house. We did get him an eye gaze. He can now access the world. He was talking to someone on Facebook and he was in tears. How much time do I have?

Sean Williams: 4 or 5 minutes.

Claire Turnbull: A couple of the young people that we work with -- we have loads of examples of the work we do. Some of the steps are very, very small. There's a young man called Paul. It's a tiny significant story. A tiny step. He lives with his family. He has muscular dystrophy. He has lost other family members to the disease as well. His family has isolated him. He's never been outside. He's stuck in his bed room with little aspiration. He won't let social workers in the door. My staff has worked with him and has made small steps. They got him to set a goal to want to go out to the science center. He wants to see the stars and astronomy. With a huge amount of planning they got the bus together and for the first time she saw him out of the bed in the wheelchair dressed. It was a tiny science center. He came home and he said I want to do that again and he wants someone to help him do it. The parents have realised that he can go and it can be safe. It was a little thing. It was 2 hour visit. Months of preparation. It was such a massive thing. My colleague said he smiled and it made a huge impact on his life. We do those things every day. That gives you a high light of the work that we do.

In terms of [inaudible]. We're at the end of year two next month. We're hoping we will publish the results. We're trying hard to nurture young people's creativity and trying to get them to set goals and to dream and plan again. It's been incredibly difficult and a lot of the families and siblings have been very resistant. I think you can't think about the future if you are not going to have one. So they are anxious to think about the future. We have transitioned them to other services. They are doing well. Really we need to keep supporting that dream. We need to support -- I can hear somebody singing. I feel like I should burst into a dance. I won't do that. That would be horrific for you all. We need to keep planning with our young people.

What I have highlighted is we need to get from "there's nothing out there" to supporting the communities and develop more services that are fit for purpose -- I don't want to be too negative about Scotland but there's a lack of facilities for our young people. There's really a need to grow the communities to make them more inclusive which is the whole point of the conference. There has to be a huge amount of joint work. The best outcomes is when social work has been involved and we work together. It's not rocket science. That's in a nutshell a quick run through of our work. Thank you. [Applause].

Sean Williams: We have time for a quick song.

Claire Turnbull: I have leaflets if anybody wants.

Sean Williams: We have 5 minutes for burning questions. One in the back, please.

Audience member: I want to ask the team from Denmark. I see you have OTPT and you have providing rehab service to your patients. As we understand, some of the patients discharged from hospital will have some emotional or psychology problem. Who will handle this?

Female Speaker: We don't have a psychologist in our house. I think we are in some way as capable as a nurse and physiotherapist and occupational therapist to handle these problems. If it gets too serious, we are aware to bring it to the doctor or any other specialist. The patients are always in the center of attention. It's our mission to help them to a more specialised help.

Sean Williams: Thank you. Any other questions? One over here, please.

Audience member: A question to the lead for CHAS. I was wondering with the criteria people having to transition after a certain age. What provisions are in place for the next stage? Is there a limit of facilities [inaudible]? I wondered if there's another organization for that.

Claire Turnbull: I suppose there is no direct equivalent. There's no adult CHAS. A lot of people want that. What they offer in pediatric services is very different [inaudible]. We are working with the adult hospices to -- there's a lot younger people coming through. They're no longer cancer specific or over 65. They are trying to get the kit better and get them looking less old fashion. We do a lot with the adult hospice. They don't offer [inaudible]. I think that's not there. Rightly or wrongly. I think it's a different type of service. We're working with the Scottish government to recognise the needs for the young people. [Inaudible]. There's a lot of life limited conditions that young people are living longer but they still need input. Does that answer the question?

Sean Williams: I know we have leaflets and further material from CHAS and RNIB. Please come to the front. Can we have a huge round of applause for all of our speakers, please?

[Applause]