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RI World Congress
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Parallel B Menteith
Younger People and Parents

These classes are small with kindergarten teacher. Two groups those with medical needs and complex medical needs. A child with diabetes is a child with a complex medical need. A child with tube feeding is a child with special medical needs and entitled to personal assistance from one to four hours every day depending on his needs. Sounds very great, don't you think so? The question is why am I here apart from the fact that I wanted to see this beautiful city and meet you all, so as you can see in this graph, when we thought about the law and even when we published it in the year 2000, we didn't anticipate infants with chronic and severe medical diseases, so it becomes more challenging all the time, and we've complex and special medical needs. We've a number on mechanical medical ventilators in our centers. In the year 2013 we had 290 personal assistants and 98 -- sometimes for the same class. It's not so easy to find nurses in Israel and not so easy to ask a nurse who just got her degree to sit with one toddler. We didn't know what to do. We started to do routines like one nurse for three toddlers or put a paramedic instead of a nurse in a class. Think of a situation where we've ten toddlers, one teachers, three assistants in the class and the professional therapist comes in to give treatments and then the special therapists and we've three personal assistants to help with the food and two nurses. You can't call this a kindergarten. Even in a hospital you don't have so many medical providers in the same room. We know we must change something in what we are doing, so the gap between what is needed and the law is growing very fast. When I go back from here I will meet my friends from social affairs and social services office, and I hope they will agree to change the concept and the regulation and my idea is to cancel this idea of attachment for personal nurse and assistant for each toddler and have one nurse for ten toddlers thank you very much for your time. (Applause).

>> Thank you that was really interesting and I think especially because you were talking about the specialist support that you provide on an individual basis but how you managed that with the increase in numbers over the children that you have to support.

>> So as I said, we do offer more and more services all the time and also the idea in our center is that we

do accept toddlers all through the year. They could come in September when we open the academic year, but they can also come in May.

They don't need to wait. When we find a toddler that needs to be in the center we admit them in the center and get the treatment they need.

>> I think it's interesting how you said you meet the needs of so many children with all the staff that you need in place.

>> So we open more and more universities for speech therapies and we work hard to get the number of people that we need for everything. It's not easy, but I think the outcome is very how do I say, challenges us to do more and more because we find it very, very helpful for the kids and also for the families. For example, the social worker support they can come every day if they need and speak to the social worker and work out the problems, and so it's very important and all the team is working together and speak together about every toddler and one envelope that's covering the child, and it's very, very good. I think it's also very unique.

>> Yes, definitely. Well if they have more questions at the end of the session, but now I would like to introduce our second speaker who is going to talk about self-determination, vocational rehabilitation engagement and recovery from consumer's perspective. That's a mouthful.

>> Thank you it's a real pleasure to be here speaking with you today. Which direction do I look for the sign? Okay, way in the back. My name is Jessica Brooks and I am affiliated with the University of North Texas in the United States, and I am a research fellow at Dartmouth so located in New Hampshire. Today I will speak about a study funded through a mental health foundation and it's a recovery oriented research grant and when I say recovery, I mean recovery as a process not recovering from a serious mental illness, but recovering and learning to live well and be prosperous in spite of having a serious mental illness for schizophrenia for instance. With this study swell a team of individuals interviewed persons with serious mental illness and these persons were all trained a certified specialists. In the United States right now we've a new position in the mental health workforce that allows for individuals with serious mental illness to provide peer to peer supports and this often is in the form of recovery types of support groups and I'll more about that later and we can talk about at the end as well. We decided to interview these individuals since they were already on the road to recovery. Especially if you consider vocational recovery as a part of that mental health recovery process. We also cared about self-determination and so self-determination in the U.S. and in other countries is a new paradigm shift moving from previous medical or disease oriented models where providers would -- and they still do this -- tell persons with mental illness what they should be doing but it's moving and shifting towards allowing persons to advocate for themselves and encourages that individuals are self-determined and make their own decisions in treatment and life and employment. So we wanted to find out more about their thoughts on self-determination and as well as recovery in

general. And so as I already mentioned in the mental health system in the United States we are now hiring these certified peer specialists. For instance, we interviewed specialists in Texas and there are well over 900 that have been through this certification program and the reason why there is a surge in hiring and training these individuals is because now they are allowed to be Medicaid or Medicare reimbursed through our health care system. These individuals who I interviewed they are described as role models, so they provide peer-to-peer support in mental health or in patient settings and they engage consumers in treatment and help them access support, so they act as an advocate as well as a role model in a picture of success for these persons. For our study, we had three primary questions, so the first was how do these persons define self-determination and the second question is how does this self-determinant nation influence vocational rehabilitation and recovery and what factors affect these associations, so this was a two-pronged approach to the study, so we had multiple questions because this is a fixed methods study and I'm describing phase I today and we are hoping through this exploratory first phase we will be able to carry out and test these associations formally. One interesting tidbit, so we were thinking that these peer specialists many of them would have worked with state, federal, government, vocational rehabilitation counselors or employment specialists, one other title that we used, but many didn't work with anyone just self-referred themselves to these programs, so they didn't qualify for the study then, but others worked with their normal case managers who are part of their mental healthcare and those persons then specialise in employment and really help to incorporate employment as a goal on their treatment plan, for instance. Many of these individuals then are just talking about their case managers. The methodology we used was conceptual qualitative research. This is a group-based approach to qualitative research. Myself I conducted interviews but I had two other people help me with coding and I also had an auditor review at different stages of the analyses and we developed different domains, in other words, themes well core ideas and I will present the results, primary results. I don't have time to talk about all the different results today, unfortunately. Some of the comments or themes from the interview we used were they talked a lot about different positive aspects of vocational services whether it was in a state/federal program or within their mental health agency. It provided encouragement, hope, support, and it was helpful having the person collaborate and assist with the treatment plan to assist that employment was part of the treatment plan. I have a quote here. It was excellent. I mean it made me want to work harder to begin with you know? She gave me help on the encouragement and she made me see that I was a better person. And just DARS, that is the state federal program, is a great organisation. Others remarked about negative aspects of employment services.

They thought it was generic, non-individualised, unpersonalised recommendations, recommending low skills jobs, fast food service jobs, which these persons were not interested in, so it was not tailored to them. Others may be interested in that work. There was a real lack of followup in staying connected with

the person on a regular basis. Here is a quote: I felt that the options and suggestions were generic and not necessarily tailored to me and my personal goals it was more cookie cutter that you know anyone can do this without any skills or education or training. You need a paycheck so let's just get you a paycheck. It was a means to an end. Another theme that came out, persons talked about how they built this working alliance relationship.

They felt that adequate time needed to be given to develop this relationship between the client or consumer and the counselor. One quote is when she realised that I wanted to go to college. She was like okay, this is a little different than we talked about, so she had a realization, this person, but before that they were having struggles developing that rapport. It took until like the sixth or seventh visit I had with her. Another person said, I would have to say the relationship has to evolve. Attitudes toward employment another major theme with the core idea being values. Some person said that sufficient time for self-care and other activities needs to be incorporated in this employment plan, so that needs to be taken into consideration.

They need to be feeling appreciated and welcomed at the workplace. There needs to be opportunities in the workplace to pursue their own passions or interest. Most people actually did not mention pay or advancement opportunities which was interesting to us. One quote I talked to my doctor and we discussed me working part time and I thought I could do that and not work a full time schedule and not full overwhelmed and so this person felt it was good to work part time and have time for themselves but that wasn't the case for everyone. There were individual incentives that were mentioned. Many people wanted to feel productive.

They wanted to have a structured meaningful day. Many had family members they needed to support whether husbands or partners or children: Many talked about improvements to self-esteem they were seeking and had because some of these individuals went through the training program and were unemployed but many were employed so we had different views and perspectives in that regard. Many were seeking autonomy and independence which reminds us of self-determination. I will read this. It was a financial thing for me but also a self-esteem thing. I wanted to be independent when everything fell apart in my life, my diagnosis and just not being able to do anything. I needed that many my life to feel I was part of the society and I was worthy. Having a job and being out there makes a person feel good about themselves. There were social incentives many talked about how they wanted to help others so for altruistic reasons this was meaningful to them and was a motivation.

They wanted to be a part of society. Here is a few quotes. I didn't want to sit at home and be a home body and isolate from the world. I wanted to get out. Another quote: I have to feel like I'm doing something that makes a difference that I'm putting someone's needs above and beyond my own. I also asked about if disability benefits, so these government benefits if they interfered or impacted the

individual's decision to go back to work, many said no, it didn't have any effect. Many chose to work time and felt it was okay to do that and receive benefits because they talked about how they have a chronic condition. Some spoke about anxieties at the beginning before they had benefits counseling or education on how to work while remaining on benefits, however, many did want to work full time and get off of their benefits. Here is a quote from one. This is the first year I will probably go to 29 hours because I feel confident if they review my case, in other words the government, they can see everything that is in there that there are no big changes and my recovery is moving forward. I don't think it will affect my benefits so that is my plan for 2016, so she is slowly planning to work off the benefits. Then I mentioned at the beginning about definitions on self-determination many said it means being self-driven, motivated to reach potential, having your own self-awareness or incite, having confidence, a positive mind set and being an advocate for one's self-and others. Someone said I would define it as having a personal drive. How can you take one more step? How can you find motivation to take one more step and then continue to take baby steps. Many said that stigma did not really have an effect on their decision to go back to work and it actually really spurred some people to go back to work and prove society wrong. View of recovery going forward. Positive thoughts and a lot of peers called this stinking thinking. I don't have time to read this quote but some talked about needing to have a healthy balance and that should be part of recovery, work life balance. Many had family members and having peers with other mental illness in their life was helpful and finally needing intrinsic motivation seemed to be a part of what motivated these persons, altruistic like I talked about earlier. Many wanted to work toward mastery and they continued to go after many continuing education credits so they would be constantly working on that. Many gave different advice to consumers. I don't have time to go through this, but encouragement for their peers. Some gave advice to service providers. Don't give up on your consumers be patient, make sure it's individualised. For the future, I am planning on a second phase to this research exploring if there are -- self-determination and recovery along with these vocational rehabilitation constructs as well as in the future there could be an inner v designed for vocational rehabilitation or in the workplace organizational behavior or psychology training or intervention program could be developed, so I'm working on these different stages and I was inspired with my second phase to interview people who were already employed as peer specialists to see if these persons are self-determined and if that's affecting their job satisfaction and their other employment outcomes and how they are doing with burnout, etc., and then trying to develop a training program also for them, so that's it for now. Later if you have questions I'd be happy to answer any of those. Thank you. (Applause).

>> Thank you, you brought up interesting points there, the benefits of self-determination, peer support and you know the positive outcomes of people going into work not just the fact that they are doing a paid job and it's not just about the benefits they receive from a calorie, so hopefully we can have an

opportunity for questions at the end.

Okay, so I would like to move on to our next speaker, which is going to talk about subject of parents partnership with service provider and enhancing service quality and advocating policy changes.

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>> Good morning ladies and gentlemen, we come from Hong Kong a special administrative region of China, which is 6,000 miles away from here. Today Illya and I will present a topic -- parent's role and contribution in enhancing service quality and advocating policy changes. We will use story telling -- I'm Becky the executive director of Fu how long society. I joined the society several years ago. Illya is the eldest service of a service user. Her sister a severely disabled person received service from our society several years ago. We are serving about 3, 600 users with roughly 1,000 full time staff and receiving 85% from the government. Persons with severe intellectual disabilities their parents or family members will speak on their behalf. In this case, parent participation means user participation. Illya is going to tell her story about how user participation is realised.

>> Thank you, Becky, ladies and gentlemen, my name is Illya. Here is a picture of my sister. She is autistic and has the mind of a 1-year-old. She loves perfume and shoes. I find myself buying her new pairs of shoes every other month because when she is happy, I am happy. Here I would like to present is overview of parent's participation. In the '80s parents were passive participants. There were set arrangements and no questions asked regarding policies because we don't want to be seen as troublemakers. In the next two decades more experience interacting with staff and support from society formed unit based parent's group. The word parents includes sibling because parents are aging and we've passed on. In the next ten years Fu how long society invites parents to engage in service level work, persuade government to make policy to meet changing needs. FuHong society values the various uses, promoting parent participation and wants to understand our aspirations and address our concerns. Parents think we understand and know user's needs and well-being. Parents groups were formed to share concerns and bond socially. The still is open and positive. Proactively encourage parents to join unit based working group to monitor service such as service quality, safety, and meal service. The parents with join Fu Hong parent's association. Currently we've 450 members actively engaged in training programs and organised activity. Fu Hong society invites parents as members of various committees. To show the significance of parent's participation, a parent representative has been appointed as board of directors, the highest governing body. This level of parent participation is unusual in Hong Kong. As a member of the parent's association I would proudly say the agencies innovative, transparent in it's management, caring and sincere when working with parents. Community level: Parents succeeded to government to pay for disabled persons and other user's need. We are grateful that Hong Kong government has increased financing to funding and increase in shelter workshop for workers. Parents also succeeded in getting doctors to visit care home

regularly for free. Parent's association recently submitted papers to Hong Kong government on the impact of aging youth with intellectual disabilities on rehabilitation services to appeal to government to address the problems. In 2007, Fu Hong parents form the alliance for residential cares for better resources, facilities and government policy changes. In July 2016, the alliance established a platform for direct dialogue with government and on going meetings will be held. So far government officials, legislative counselors, seem receptive to our concerns and issues raised. Here I would like to make a special mention of Mr. Lysing. The one circled in red on the next two slides, chairman of parent's group. He organised positions to seek government support to better the welfare of disabled persons and the elderly, increasing residential placement, cash allowance to caregivers, increasing manpower and resources in services; as a result, government has implemented a public transport concession scheme for persons of 65 years of age and persons with disabilities of any age. Second, subsidies of 5,000 dollars to disabled persons and third, recently, we succeeded in getting the Hong Kong dollar 2,000 to caregivers as a monthly allowance. We trust the combined effort from government, society, staff, and user representatives, will bring a win-win outcome for all. Thank you. I now pass it back to Becky.

>> After learning what parent participation in our service context in what way it is contributing. Let me elaborate the outcome. Parents have been users and they understand the needs of their family members they best represent and speak for service users, give comment to provide the user quality of life.

They identify service gaps and make concessions for new service provision. Second, parents helping parents, through social interaction, parents know more about needs and they can render assistance to others who need information, knowledge, skills, and service in caring for personal with disabilities. Third, more understanding and trust with open minded communications and cooperation between the parents and agency staff, more understanding and mutual understand between the two parties can be developed. Four, parents can mediate conflicts and crisis between parents and the agency or among the parents as it is easier to be accepted. I remember about ten years ago when I was in charge of the center there was a campaign against me for ten counts of fraud and mistakes at work. While the agency conducted a investigation and found none of the accusations against me was substantiated -- I was so impressed and grateful for such a supportive action by the parents. Fifth, parents helping the agency with increased understanding of and commitment to the agency's service parent members give their views and comment on service development and even as ambassador of the agency. They have introduced and promote agency's work and built up good agency image. Besides the parents also involved in the fundraising activities for developing an maintaining services. Sixth, parents are part of community. As we've just learned our parent representatives are actively taking part in community action, not only to benefit the current users but also those to be in the service. So far we've seen this successful and encouraging development of parent participation and now let me summarise the key success factors. On the agency

side, there are at least five key factors which are first the agency's clear mission and belief in user participation. The corporate governance and opportunities given for realization. Second, crucial for the agency to show recognition. This is made consistent through mutual trust. Third, agency needs to be open minded and willing to collaborate with parents and respect their views. Fourth, open and friendly communication among and between parents and staff are necessary to maintain relationship and trust. Timing and appropriate feedback is important for caring and understanding. Fifth, regarded as the most important factors by the parents is the agency promise in updating information and to share facts it is therefore the policy to inform the parents of any mishaps. Incidents of injuries in particular at the earliest time possible.

>> On the parent's side Rome was not built in one day and so is trust and faith. We've to accept and understand what agency is doing and can provide. We expect our users to have a normal independent lifestyle and accept agency's restraints and limitations in service provision. We try our best to contribute time, effort, knowledge, and expertise to help users, parents, as well as society's staff. We believe in working with the agency in service planning and delivery and we look forward to contribute alongside the agency in service provision. We believe in synergy creation and continuous service improve. Yes, we can build a better place for our users.

>> Thank you Illya. The experience of our society in the last 30 years has proved that parent participation and involvement at various levels are successful. To conclude, it has proved that voice of parents is now clear and impactful and it should be respected and seriously attended to by the service provider, the government, and the community. Second, parent participation has contributed to effective service partnership, not only as parents as important stake holder, parent participation has become a priority in service objective setting. Third, parent's attitude should be cultivated and changed to make it a responsibility to contribute one's experience and expertise in the development of the need and improved service not only for all family members but also others who need the assistance. Their contribution is much more powerful than previously conceived. Finally, we've a successful experience as a service provider, we've stronger belief parent participation and their powerful impact could bring fruitful results. We would be happy to share our incites with colleagues to benefit other users as well as others who are still needing the most essential services. Thank you. (Applause).

>> Thank you. We will take questions at the end of the session. Now I would like to move on to our fourth speaker which is talked about handling autism, children, and acute diagnosis, appropriate education, treatment and strong support.

>> Hello, I would like to introduce my team and invite you

>> This small island is Bali. It is geographically a cross between the Pacific and Indian Ocean and bridge two continents Asia and Australia. In the year 1945 -- oh my, sorry, sorry, sorry. Those who have any kind of

disability are eligible for special education. Everyone has the right to obtain the safe, quality and affordable health services. We've act number 8 of 2016 on people with disabilities and this is the general for the rights of persons with disability. Autism is a complex developmental disorder with the specific symptoms. There are really autistic spectrum syndromes, the accurate diagnosis as early as possible is necessary and then they need appropriate medication, education, treatment, and strong support to make them independent so autism school, autism clinic, family and community and inclusiveness. Then let us see a step of appropriate education. Handling autism children is individualised because each individual has a different characteristic, different problem, so we've to do one on one and select them to transition school or special school or to the inclusion school with the adjusted curricula with or without shadow. Principles of medical treatment: They have early intervention, continuously, gradually and in accordance with the child's development. A wide range of government treatment which is medical therapy, biomedical intervention, applied behavior analysis, sensory integration therapy, occupational therapy, speech therapy to improve communication and the applied behavior analysis is for their behavior to make it acceptable to the community. By increasing of the public demand for services and specifically, consequently, the rights of autism clinic and school and you know there is no policy governing the health care for autism specifically, so implementation is different in wide range in accordance with perception and availability of resources. We are from the organisation Indonesian society for the care of children. This is the first society for this. We feel responsible to provide school on the clinic for disability children in the school. This is the school for autism children and the challenge begins with limited funds. We see this is the old building and the transport station, it has gradually developed towards an education and healthcare center for children with autism so they can live independently and productively. The important one for my organisation aspire that Mitra Ananda will be able to contribute to help the government in formulating policies that are specific to the education and care of children with autism, to provide an opportunity for researchers to do important research which is needed and is a reference for autism schools and clinics in Indonesia. To reach the goal we've to develop our Mitra Ananda. This is the new building. There are short-term and there are medium term and long-term plans. This is the short-term financial management improve strategy with the goal implementation of financial system. Structure organizational improve strategy. Establishment of the organizational structure in accordance with the expansion plan: Strategy improvement quality and care and quality of education. Recruitment of prospective students and users of healthcare strategy. The goal is to actively monitor and evaluate. This is the big family and they support each other. This statement is proved by the study of Zaky, and Abhy where the whole family, both parents and sibling support all education efforts at all time for independence. This is Zaky's sibling. This is his mother and Abhy is one of the winners and let us see the support of Abhy family. This is important. Applying the rules at home that should be followed by the member of the family, so Abhy understands

norms and regulations. Giving Abhy daily tasks that become obligations. Third, help find a way if he finds difficulty in performing tasks of social, academic by giving an example of divert things that are visual. The provision of support also gives a challenge to acquire the skills prefers, don't focus on shortcomings and involve family and social activities to help him to deal with sensitivity to the crowd and encouraging him to find ways to cope with their own business. This is Zaky. He is represented by his mother and support for Zaky will be presented by his mother and his sibling. Thank you very much. (Applause).

>> Thank you, and again, I think what came through that presentation was the importance of family and parent involvement in making it the education success. I would like to open up the floor now and ask if anybody's got any questions that they would like to ask our speakers we can spend a few minutes just spending time with any questions that you might have. Okay. We've two people. We are going to bring a mic. over so everybody can hear. Yes, for the typist.

>> Just a question for Jessica who did the university research you mentioned that you were hoping to lead to other research and a training program. What would that look like?

>> Sure. Hello, is it working? So, the training program that I'm working on developing and seeking funding for right now is influenced by the organizational psychology, organizational behavior literature and there is a training program that has already been developed out there for the general population and it's called psychological capital training, so there is an influence then of positive psychology with that, and so the training program that's been developed has been both in face-to-face and in web-based formats but I'm working on developing a web-based format at first and then this program would actually, the plan is to implement it and offer it to mental health providers so three different groups actually, so one group being peers and nonpeers, so they would be integrated in the same module or the same program, and then two other programs, separate programs. One for supervisors of peer and nonpeers and teaching them how to encourage and develop positive psychological capital to prevent burnout and low job satisfaction, and the third group, I'm collaborating with someone from Yale university who has done work in the behavioral workforce for years and she proposed a third group and this would be to train HR, human resources, these hiring managers as well as other higher level administrators, so three different groups. You're welcome. Thank you for the question.

>> Thank you. We've someone else with a question.

>> My question is for Hadesh. I was interested in that program you're doing in intervention and the holistic approach to supporting the individual and a group of people that can support their needs with that representation. My name is June and I represent first people's disability network of Australia. What we've seen in Australia, particularly our indigenous groups with children with high support needs, the first thing our government does is remove the children because they don't see the supports that the indigenous groups can support that whole community approach, particularly with children with high medical needs. I

was interested that you said you sole support at home with these policies so it's not only in the centers, was that correct?

>> First of all, thank you for your question. These centers that I mentioned are for children with a developmental delay, not with medical problems only. For example, a child with cancer or something like this is not for this group it's only for development. Usually the treatment is all in the center, but they do visit the people at home.

They go to the parent's home and talk to them and ask what times they prefer them to come. Sometimes in the morning or in the afternoon but they want the child to be in the house so they can see the environment at home. When the child is developmental delayed but he can't visit the center because he takes a medication that brings his immune system to a low level or he needs very special treatment that needs to be around the day, we think that the center is not a suitable place for him, so we do give the family assistance to come to the house and the assistant is staying there for all the day and all the year to is parents can go out and then the insurance company, health insurance company needs to send their therapist to the house and gives them the therapy at home. Mainly, we want the children to come to the centers and also some hours during the day we send them to normal kindergarten to be with other kids. We want them to be able to go maybe to usual kindergarten and then to usual schools and be part of the community.

>> So I think the second part if it's okay of my question was, and that's how I understood it to be, which I was interested was when you're dealing with your indigenous, the ones that maybe live a different lifestyle and you're supporting them in the home, you know culturally that's the part I'm interested in. How do you support them in the home. You know the acceptance that may be different.

>> First of all, we've a very strong relationship with the community and we do speak to the leaders and find out what is suitable for them because you can't go into every house. There is some places that it's not in their tradition to invite you to their house, so we really need to find a tailor made treatment for everybody and they know what is good and what is wrong to do. It's not very easy. It's very challenging we do have problems every day and we really try to find the best way to fix it and to learn from it, but we learned a lot from the year 2000 but we are still learning and we are adding more and more things. For example, we just added the nutrition support and treatment because we found out that most of the kids with disability with developmental delay maybe the first things the parents notice is difficulty with eating, they don't eat solid food and they prefer something and not the other and we find out that giving the nutrition support is very important for the parents and for the child, so we are learning all the time and adding more and more things all the time.

>> Is there a paper on this that we could look up, you know, online for the Israeli government of health?

>> We've a minister of health web and also in English an everything is written there and if not I can send

you.

>> Thank you.

>> Any other questions from anybody else? You've gone silent. If there are no further questions I would just like to ask you just from the presentations that we've had today, do you think there are emerging themes about what we as people who work with disabled people or support providers, parents, family caregivers that we should stop today, is there anything that has stood out today from these discussions? Hang on, I must give you a microphone.

>> Hi, I think it was interesting that the common theme with all the presentations, which thoroughly enjoyed, that you need the support of family or to support the family unit to improve circumstances and to start early and we hear it's a common theme all the time, and really, we need to get back to the general fundamentals in life, and that's about family and culture and early intervention and they are all common themes really with the right supports we can have better outcomes.

>> Yeah, I think that's what stood out to me really how important it is to involve the family members and any decisions and to take positive steps forward with any services.

>> I just want to add the woman that asked about the culture, so in some cultures in Israel -- they used to hide the children and sometimes it disturbed the marriages. What we are trying hard to do and where we are starting to succeed is stop hiding these kids and go to the places where they can get help and we are getting there slowly.

>> Definitely.

>> I really agree with you. It's because back home in Indonesia they still do that, and it's such a fight for us to be able to you know, tell them that something is not wrong. You just have to get out, get help, get support because there are people that actually care and can help. Culture is a big thing and every place it's so different, it's so diverse. Coming here it's a hope that we can actually do better even though there are other variables to think of, but I just want to say that it's such a great opportunity, it's such an eye-opener for everyone and it gives us all hope that everything will be okay.

>> Brilliant. Fantastic. Thank you. So do you think there is anything that we should particularly continue to do from the presentations today? Is there anything that stood out for you? Gentleman at the back.

>> I'm sorry, you skipped ahead of me. I wasn't expecting that. You were on the subject of things that were observing during the conference. I think it's a great conference. I can't believe the side and depth and the broadens of it, but one of the things that disturbs me is our language and I think we really need to be active and do something about it because language does penetrate family beliefs about themselves, about individuals, and yesterday was a glaring example of speaker after speaker after speaker talking about disabled people. I think we need to talk in people first language and we need to take that seriously and we need to reorient ourselves to something we really learned 25 years ago and somehow it's dropped

out of our language. I think the other thing that wouldn't be popular at this conference, but to me is the evidence of the word rehabilitation. Rehabilitation conjures up the idea that there has been something happen after a person is born and therefore it's either their fault or society's fault or whatever. Many, many children and families have issues from birth and it's not really a matter of rehabilitating them and it also has a lot of connotations in many societies with things that people have done have has been illegal, so we are going to rehabilitate prisoners and drug offenders. I think there is some positive things in our field in the work that we do that we should try to look at those language issues.

>> Okay, if I could just respond to you about the language. The people with disabilities or disabled people comes from the models of disability and so if you're working from a social model of disability, you believe that society disables you and that's why you use the term disabled people because you're disabled by the barriers that exist around you, not by your medical condition, but I also understand about people first language which is about people with disabilities, and I think this debate will go on for a long time about whether it should be disabled people or people with disabilities. Yeah, I think this is a perfect forum to have these discussions and it's important for consistency in the language that we use because as you've identified just by the terms we use can have negative influence and impact on the people we are talking about in their lives as well, so that is one of the things we must start doing is having consistency and international agreement on the best language to use would be beneficial for all people. Okay, is there anything else that anybody would like to ask? Okay, well if there is no further questions I would like to draw this session to a close lunch is waiting, so I would like to thank you for all attending and thank you for your time and very much thank you to all our speaks all our speakers today. (Applause) (end of session)

>> Let's get started. So thank you everyone for coming to this session on rehabilitation. We are going to hear from four speakers talking to you about some really interesting topics from gait analysis through to hacking wheelchairs. I will present each speaker and invite them to take the podium. After each speaker's presentation you will have five minutes to ask questions and at the end if there is any additional questions you have, you will have the opportunity to have questions then. We will have someone with a microphone and will bring that to you, if you'll say where you're from and state your name and your question then our typist can pick it up on that screen. As you heard in the opening session, we will be taking feedback from today and the feeding that into the closing session. In particular, we are interested in hearing about what you want us to stop doing, what we need to continue doing, and what we need to start doing, so if you have comments or points based on the presentation that you want to feedback into the closing ceremony, please do either your questions or at the end of the talk. I'm Gemma hope by the way. Without further adieu, I will hand over to our first speaker. Gwen who is talking about development of a hospital-based

gait analysis system. Can I invite her to take the podium. Thanks, Gwen.

>> Thanks. So today I'm going to talk to you about gait analysis can be used as a rehabilitative tool in a clinical environment. First of all, I will explain what it is. It is a method of analyzing movement and the way that humans walk and the technology that we use to do this can be used to analyse any other type of movement. What we are looking at in particular are the schematics and kinetics. So this can be done in two or three dimensions. Because of recent advances in the technology, three dimensional gait analysis is much more common nowadays and the way we do this is we place retroreflective markers on the skin of individuals and they represent landmarks and we get them to do certain tasks in front of infrared cameras and we can use special software to track their movements and calculate outcomes that we're interested in. We do this to identify pathological movement patterns and if we can identify where the issues are we can then use this information to guide the rehabilitation and treatment programs so the aim is to improve mobility in patients who have disability. It's not very often used in clinical environments and this is because the current protocols have a lot of disadvantages so gait laboratories are typically massive empty rooms and hospitals can't accommodate this type of space for laboratory. Also the protocols are very time consuming so when an individual comes to the lab, they need to get changed into tight fitting clothing and so the markers represent their bone underneath and that is problematic and so a lot of people don't want to do that, and once you have done that, you need to put the markers on to the patients which can take time and then do the assessments. After the assessments themselves you need to go through the data and frame by frame and label all the markers which can take hours and the data itself that you analyse after is complicated and all in the form of graphs, so if you are not someone who studied biomechanics you might not understand straightaway what the data means. Because of all these limitations clinicians often don't get training in how to use this technology, so that is another reason this isn't used in hospital environments. Some of the technology as well is expensive, so that is a limitation in itself. As a consequence there is limited accessibility to gait analysis technology which means that a lot of people who could get benefits from it are not getting the correct assessments they should be getting and with that there is limited evidence of effectiveness of gait analysis in clinical fields. So why should we use it? It is a gold standard method of analyzing human movements and one good thing about it is that it is noninvasive, so it is a good assessment that could be used in a clinic. Also you can measure a lot of different variabilities at the same time and get information on how functional a person is, so someone of the assessments that are currently carried out in hospitals are under static conditions so you don't know how mobile the person is. What is also good that I mentioned earlier and we can get information to guide rehabilitative treatment plans and recent zests have shown that people who have under gone gait analysis have improved functional outcome following a treatment in comparison to those who haven't. One reason is patients can get feedback of how they are doing before and after treatment and this can be encouraging and have them

understand why they need to do certain physiotherapy and certain treatments to improve mobility. The same of my PhD is to develop a clinic appropriate gait analysis system to assess lower limb function and I'm particularly looking at patients who suffer from knee osteoarthritis. The first thing I want to do is make a small scale lab that can fit in a hospital, so instead of them having a big open room we've now developed a little treadmill that can be used in a hospital room, so ours is in a physiotherapy gym our surrounded by cameras that can track the movements of the person. All this can be done on the treadmill. I want to make the marker simpler to use. Instead of using individual markers we use clusters of markers to track where the bony landmarks are. You point at the landmarks instead of putting the sticky markers on, so this saves time and also means that patients don't need to change into revealing clothing, they are just wear what they are wearing when they come to the hospital. Because I was looking at knee replacement patients I wanted to build applications that would test outcomes of interest in this field. One is to see what the range of motion is at the knee which is really important in orthopedics. This was measured with a plastic goniometer and results are often inaccurate in patients with high BMI, which is often the case. I have developed another method so clinicians don't have to learn how to carry out a different assess. All the patient needs to do is lie on the treadmill and assessment can be far read out to see how far they can bend their neat. The second assessment can be done with a system to see what the strength of the knee is because we need to have Savony to carry out certain activity such as going up and downstairs, so it's very important that we now how strong those muscles are. This isn't always carried out in a clinical environment, but it's something that should be because it's so informative. Sometimes when it is carried out clinicians use dynamometers which is bulky and expensive. Again it's familiar to clinicians and all patients need to do is it on the chair and pull or push on the strap which is attached to something that can measure force and we can estimate the strength of the muscles around the knees. So as I mentioned earlier seeing what patients walk like is important, so we can get patients walking on the treadmill and we can see the angles of the hips, knees, and ankles are moving as they walk and we can see how unbalance the person is as they are carrying out this task and this can be done to identify pathological gait and with this information we can then try and improve the way that they're walking and doing other tasks such as walking up and downstairs or getting in and out of cars. This can gauge the level of mobility. So while I was doing all of this, I wanted to make sure that the whole system was easy to use in the clinic because nobody is going to use it if it's complicated. As I mentioned previously, the setup time is quick, you just need to put the clusters on and point the pointer at all the different anatomical landmarks and then you can carry out the assessments they are noninvasive and patient friendly. Another thing that I was considering when I was making that was the clinician wants to be with the patient during the assessment and not be the computer, so they can control the assessment with a foot switch as they are with the patient as opposed to running between the computer and patient. There is not need to label markers you

can get them in realtime so you don't have to wait hours to get results and they are in simple format which is what clinicians want. It is gently in numeric format and can be seen as the patient is done assessment. I have seen about 92 patients so far with total knee replacement and the whole assessment including putting the markers on and off has taken about 17 minutes which is at least an hour faster than it currently is, so it is much more feasible for a clinical environment than current protocols. To conclude it's analysis is a gold standard method of analyzing walking and human movements but the current protocols aren't very appropriate for clinical use so our method is a smaller scale system and can record the data quickly and in large time so has the potential for large-scale use. We are hoping this can be used to gauge the level of mobility in patients and hopefully use that information to then improve their function pre or post treatment. So I would just like to thank them -- for funding my PhD and to my supervisors and trial team I'm working with at the moment. Thank you very much. (Applause).

>> Does anybody have any questions for Gwen?

>> Thank you for the nice presentation. I have a comment. Did you use any balancing like EMT because if you used only the velocity and -- you can't cross refer --

>> That is a really good question, so you can get some treadmills that have the force plate built into the treadmill itself, but they are much more expensive, so at the moment we are just using traditional treadmill because if you're trying to essentially sell this system to the clinical environment and you say oh, you can buy the system but it's going to cost 30,000 pound, then they might not be as willing to do it. If you say well you have already got a treadmill, so you just need a couple cameras at 200 pounds each it is much cheaper, but it is definitely a possibility, so maybe in the future when costs come down it could be done.

>> Thank you.

>> You're welcome.

>> Does anybody have additional questions. Thank you very much Gwen. There will be an opportunity to ask further questions at the end.

Could I please invite now and I'm really sorry about the pronunciation of your name Yeonsoo Jeong the assistant professor at Daegucyber University.

>> Thank you my name is Yeonsoo Jeong from the University of Korea and in this presentation professor Kyungsoon Park and Jeong yon. The title is the legislation of act and end dependence living support for adults with developmental disabilities in Korea. Introduction, movement of parents for enactment of law, the third is research method and procedures, result and interpretation and finally to plan for the future. The purpose of this study is to support independence living of adults with severe developmental disabilities after graduating school in Korea. This study background, severe developmental disabilities is ASDD have not been provided the same support level like their school age from the government and returned home

again or entered living institutions in Korean circumstance. Recently, the movements of parents and disabled advocacy groups have been proceeding actively to settle a program center and customised support system for independence living support of ASDD. The movement of parents for enactment of law. There was not concrete act to help ASDD but there are just the relevant acts until before then. The unified movements of the parents and the advocacy groups became the foundation of supporting policy for ASDD at the time.

Many parents of children with disabilities demonstrated against the government to improve their children's quality of life and to acquire the educational opportunities, and they also demanded a face-to-face talk with the mayor of Seoul. Several parents shaved their heads and marched through the streets to accomplish their demands.

And this movement influenced on the other provinces, especially key where you know gee province near Seoul.

The parents movement and direction as a result of the legislation of act and parents movement in Seoul, now three centers were established in three districts and the education was progressing as center system for education and care program using of ASDD. instead, recently Kyunggi province suggested to apply place train model of the vocational rehabilitation areas to the provincial governor.

They think this model need for residential living, community, adaptation and vocational rehabilitation of ASDD.

Movements and activities of various parents societies for ASDD contributed to establish the act on right promotion and support of people developmental disabilities in April 2014 and this law was implemented since November of 2015. Many parents and advocacy groups participated in the improvement of legislation of law. The related photos is as follows and this is the YouTube site. These are the scenes I wanted to capture and the first is a sit-down strike of parents and advocacy groups in city or street. The next scene is shaving parents' head. The next is demand of the mothers. The next is inauguration ceremony of promoting solidarity.

After this movement of parents, the various areas of opinion were corrected. The next discussion for acceptance of the area are discussion for acceptance of the opinion, bill proposal of the act, parliament try passage of the act, and then the parents and the advocacy groups went out to the street and they cheered each other. Their demands were to study the methods, how the act can be legislated, and how their children can live in their community, and how their children get and maintain the human rights after the parents died. At that time, the government said, we will begin to consider a good solution with you. the study is progressing with qualitative research, so the participants of this study were some parents among the parents union for ASDD and workers of lifelong education support center where operation is just beginning. For this study, interviewed with parents about their activities for legislation, their demands to

the government and the policy determination contents, and effective ways for independence living and community inclusion. And this study also interviewed with workers of centers about what is most necessary education for the ASDD. What was the most difficult experience in this course?

This is data processing and analysis method. The data collection consisted of depth interviews of parents and the workers. The analysis of checking data was proceeded by a qualitative case study method. This study generated the results and interpretation through transcription, conceptualization, encoding, subtopic, and core theme. The results and interpretation: The results are generated from two aspects: The parents and the workers. Their opinion is different. The motives of the legislation from parents, children who are equal to the last railroad station, this is -- research so I use the method of priority. The children's parents said to me their children even though they teach their children but last railroad station is equal not to be denied in the society, so acquire the opportunity of continuous education after graduating school without return to home is the parent's opinion. The experience of education program operation for ASDD from workers in the center: Doubt and disbelief about adults education, look of the surveillance of parents is the worker's opinion even though an Ernest desire of appropriate educational program by various area experts, and they hope understanding lifelong education as the continuous education. In my country in Korea, we divided the lifelong education areas into six areas: Basic literacy, humanities and refinement, vocational education, citizen participation, and culture and the arts. They have a joint opinion about future improvement plans. Control tower and cooperation between the organisations. Special education, vocational rehabilitation area, social welfare and lifelong education of general. They suggested about these areas cooperation and cooperative system for program development from inclusion to engagement and various researches and the studies for continuous education. They think that continuous education is a lifelong education for ASDD. Thank you. (Applause).

>> Thank you very much. Really interesting presentation and good to see the law was changed in Korea for the legislation. Does anybody have any questions for the professor?

>> Do you have any questions?

>> Okay, well there will be an opportunity to ask any questions again at the end if you do think of something as you go along, so thank you very much. We are now going to here from Justin Brockie who will be talking about practical applications of leveraging web based software in provision of inclusive support worldwide.

>> Thank you, my name is Justin Brockie and trained in what was known at the time as a registered nurse for the handicapped. I worked with people with developmental disabilities all my life. I moved to the United States about 20 years ago and having worked there a while, I joined a software company called Therap and we've developed a system used by direct support staff primarily for doing what used to be written in books and on sheets of paper and things like that and we've had 13 or 14 years of experience of

seeing the impact this has on the lives of folks with disabilities themselves, their families, their friends and their communities, so I would like to give you a brief introduction to how that's going. We now have 13-14 years into this and have records for over 300,000 individuals all across the United States as well as in Bangladesh, Sri Lanka and Nepal. When we started our model was, and again -- living was our thought at the time and we thought we will have an Internet-accessible computer in every group home. This called consternation because people said you can't use the phone. We were also told if it's not socially normative to have a computer in your living room. Things have changed. What we were seeing at the time was the solution to this problem was cloud-based computing, which again, 2003, no one cared where rain came from and where the Internet came from. We've moved on and our basic supports for why and how they are provided is mostly everybody has an Internet device in their pocket, and I suspect most of you do, and rather than putting something on a piece of paper which can be given to someone else to enter into a computer system, why not have the people providing supports enter that data into the system as they go along wherever they are as they are and giving you the ability to support people wherever they live and work. Really it's remarkable. I'm also the parent of a daughter with fairly profound disabilities, and the amount of information that is required just to be a parent these days is quite remarkable and if you're an NGO providing services just enormous amounts of data that need to be tracked around the person, and what we've done is developed a web-based application that has somewhere to put all that and because it's cloud computing, all the hard work that would be required for you to do that yourself is taken care of. That's out there on the Internet and no need for installing software or maintaining software, all you need is a browser and a phone. Over the course of the last few years in the United States, we've been granted a few patents on this, so particularly with regards to how do you share the data between multiple organizations. The average person with a intellectual disability is probably receiving supports from three or four different organisations, how do they communicate securely and in realtime with the right information and the right people. A few statistics: I like these numbers because it shows that it is actually working. We've a thing we called the t-log. And that is just a communication note that a member of staff might have left for another, and the moment we are running around three million of those getting written every month in the system, which is quite a lot. The really interesting thing about these notes is on average each one of them is read 12 times and if you are in a residential care home or something like that where notes are getting written in books they are getting written and nobody is looking at them, so that change in communication is the factors we've seen. There is so much less of this, well, I didn't know that and nobody told me, because people are able to process this. Just in terms of the data we've every day a million leads of t-logs so a million note reads are going on every single day inside the system. This ISP data is people taking measurable data that can either be calculated on afterwards to compute progress towards outcomes, learning skills, getting to places they need to be and can be used from a billing perspective, so if

there is a funder involved and they need to know how much service was provided it can come out of that and you can see almost 8 million a month. Instant reports bad things happen unfortunately, but there is a process so that rather than having to wait for a piece of paper to get from A to B to C to D and in order to be able to react to that can happen in much more realtime because we are all online. Because it's the United States everything costs lots of money. Most of the people we work with are providing Medicaid services so they are funded by the government through what is effectively social insurance, and our customers are billing about 1.5 billion worth of services every year through that. Again relying on this data to make sure they get paid for the services they provide. This one because it's a scary big number. We've a medication administration record, somewhere where staff usually not nurses, but rather trained, unlicensed staff are passing medications to the people they are working with and every month about 13 million medications passes are documented, and again, that's critical data. That's people trusting you with people that really, really matters. Again, as I said, we've gone very much from having done things on a desktop to doing things on laptops to now a vast amount of data is collected on phones, and some really interesting things have happened some of which we didn't predict when we originally started. These are two ladies supported by one of our customers in the buffalo, New York area and they came to one of our conferences to talk about what the impact of using Therap's web based system had been on them and their families because not only did they and their staff have access to this data, so did their families. The big thing that has come up on this is the improvement in the relationship between families and support agencies. Okay. My theory on why this is is that family members of a person with disability who is in care have lots and lots of really small questions. They want to know oh, it's colder today than yesterday, did they remember to put their jacket on? How did that appointment go? Are they still feeling with well? If you call the group home or wherever it is your loved one is supported every day with three or four of those questions pretty soon you become annoying, so the staff become resentful and you become resentful and things break down, whereas if you can just go online and get the answers to those simple questions, then that's done and you don't have to be worrying people and that leaves the conversations for dealing with the big, important matters and we have had this happen time after time after time and it's quite interesting because I will talk to people and I will be saying yeah, what you should do is give the mothers and fathers of the people you support access and they give me this look like I must be out of my mind. It's the same look I see every time. What I've learned is they all have one particular mother they're thinking of, one particular scary mother they are scared of and thinking I'm never giving access to this data that our staff write before we vetted it. I point out to them that scary mother is actually my wife and she is the one calling every day asking things is the one you want to do it with first because she is the one with those hundreds and hundreds of little questions and if you can get that information out, she is going to end up liking you a whole lot more, and time after time around the whole country, we've seen that happen that

those formerly afraid of mothers are now becoming active parts of teams because the communication is really going better. The other interesting sort of thing from a therapeutic perspective when you're giving the people you're supporting again realtime access to the data they are looking at, it forces people to write documentation in a manner that is respectful. Support agencies spend a lot of time and effort trying to teach their staff to write in-person centered language and usually not very successfully, but if people know that mom is going to read and that person themselves is going to read that, they are likely to write it in a more humane way. If you're supporting individuals with behavioral challenges and they are going to read things that were written about them later on, it becomes a very interesting dynamic. If I have had a bad day and ended up picking up a chair and throwing it through the window, I'm then going to have to deal with that later on as I read the note that says I picked up the chair and through it through the window. I will have to take responsibility for that and deal with that. Lori did interesting talk about how things like that impacted her and provided a new focus on what that documentation is and what it does. Just quickly just to go through the folks involved in this and if you're interested I'm downstairs in the exhibit hall and I would be delighted to talk more about this stuff. We've a number of agencies and seven states that use the system now across the entire state for supporting their services for all the reasons you can imagine, getting that incite to what's going on. Our primary customer is the provider agency, but more and more getting to the parents and family members and the self-advocates themselves awe lowing people to really take more ownership and more control of the supports that they are receiving. If you're going to be self-directed in the supports that you're receiving, somewhere along the line you are going to want to be able to measure that. Let me just go very quickly to here. What we can now do based on this is some really, really interesting data analysis in terms of how are people actually progressing, what are the things that are happening that are doing people good, and what are things that are happening that are not so good for people but are happening anyway, and we can do that based on real data collected at the point of service. With that, thank you very much. Again, I'd be delighted to answer some questions now if you have them or chat with you downstairs afterwards. (Applause).

>> Thank you very much Justin. Does anybody have questions?

>> I work in Pakistan in a center for children with disability and we do keep your data in soft copy, so we are fans of keeping data properly written, however I have huge concerns about consent, about interference from outside agencies like Therap has more data, who is giving them the consent to hold that data in people? The fact that parents of adults will have access. I just find this whole big data thing, insurance companies have the access, there is some things here where the disabled person can be quite easily abused and that's a huge problem for me. I totally agree that we've to keep good records so that we can keep an understanding between different agencies but this idea that is held in the cloud worries me.

>> I think you have to be very, very concerned about data security, but here is what my take on this has

been based on a lifetime of providing these services was in the last agency I worked at which was paper based completely. I thought of the abuse and neglect investigations, you had no idea who had looked at that. There were documents left on people's tables.

>> But I'm saying we don't do that. We've our own server, secure server, so we within our organisation and we've an access because parents are the guardians of their children and when they get to older adolescence there are privacy issues here and it is the big data going to all these other organisations that worries me because we cannot say that the cloud is secure we see it in the tabloids all the time about thing getting stolen.

>> The cloud is not a single place. This data is stored on servers that we own and maintain in a location that is ours. So security is obviously a big deal but I think that is a big deal wherever the data, not casting -- certainly someone can hack in, nothing is hack proof and for the social service agency to be able to forward the degree of security they need around that data better to have it in a shared environment.

>> What are your responsibilities as a company not to use that data for your own promotion? What is your ethical position about using the data you've used today about I can tell you this and this and this, where is your authority to use your data of all these different organizations for insurance companies? I do understand that we need to plan, but I'm just --

>> I'm a big fan of skepticism. I am. All I gave you was counts of events I didn't come up here and tell you what's going on with anybody. Most of the work we do is in the United States and is covered under two or three major data security laws that say what we can and can't do. It's interesting. We are having internal discussions just now because we basically don't do anything in the way of studies on the data. Our view is the data belongs to those people and so as it were we've had a number of universities say can we run a study on that data and our response is always no. The insurance companies get very, very limited event based, you know, was this service provided and that data is going to them anyway, because it's billing data. They don't get access they send the data the customer needs to be paid, so we don't do any of that. There is an interesting question of we are now looking at how could you get predictive with some of this data? Could we use this data to say this person based on the things that have happened to them over the last X weeks or years this is likely to happen. That potentially has some huge benefits, we are just not sure whether we can use that data in order to do the studies to see if we can make that happen, and so we as a company, our personal corporate ethics say we don't use the people's data unless you can and it is actually up to our customers to get the consent for the individuals whose record is going in there and the data itself is controlled you know, I think if you can compare the way we store data to the way something like a health information exchange would store it, very different access mechanism. It is default to -- if you go into the hospital, for example, the doctor in the hospital needs to be able to see. You don't want him to have to wait for access to your record. With ours you only get access to the specific individuals you have

the right to see.

>> Thank you for that robust question. Anybody else have questions? At the front please for the microphone.

>> I have basically a similar question. So you said that the app is now on the phone. How easy is it for me to go into your phone or anybody's phone and get data?

>> Again good question, but it's almost impossible. For a part, none of the data is stored on the phone. The data is continually stored in our servers where it's encrypted. All the data moving is encrypted and all the data at rest is encrypted, so there is nothing there. Your phone is just an access. It's one of the reasons, some people would like us to have an offline mode so you can do things when not connected to the Internet, but then you end up having data on that device which is something we don't think is a good idea.

>> Thank you.

>> Thank you.

>> Anymore questions for Justin.

>> I have a question about implementation. I am from the Netherlands and I noticed a lot of different ideas about collecting data about serving the customers, the parents and the people, the professionals. We observe a lot of resistance, mostly with professionals. They are afraid of Internet, afraid of digital data and the afraid of everything to do with computers mostly so what barriers do you see and how do you overcome them.

>> That is a great point. In general we find that the direct support staff who tend to be younger, basically you don't need to teach them anything. You give them a login name and password and point them at the app and they move forward. Traditionally it's the director of nursing who says I became a nurse to look after people not to work with computers that is difficult. What we found is when they start to see the data that they could never see before, so if you can imagine what a community nurse has to do by the time they spend driving to find bits of paper when they can see data in realtime for all the people they support, that tends to be what convinces them. It takes time and a very hands on approach we've a lot of support staff training people in the field. One of the things I've learned is people get invested in their paper forms. They have spent the last 20 years making this perfect and when you say you have to stop using that form and start using a computer instead, there is a little bit of grief that goes on during that, but generally I think it's results based. When they can do things, we have had nurses saying they are saving two hours a day which is invaluable.

>> Thank you very much. Now can I invite Molly to the stage. She will be talking about hacking wheelchair with digital fabrication

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>> Hi, I'm Molly from disruptdisability and I'm going to be talking about our project HackOnWheels which is

a community-led initiative to develop open source design for wheelchairs I'm going to give an overview about how and why we started disrupt disability and the problem the problem was as we saw it and where we got inspiration from and where we are today. Thank you.

So the former director of disrupt disability can't be here today because she is at Stanford studying for her MBA and that is Rachael Wallach. Our story began when Rachael was traveling in Cambodia and as a wheelchair user herself, she was surprised she wasn't seeing have much other wheelchair users out and about on the streets in Cambodia. So being curious she tracked down different organisations there working with wheelchair users. And through a number of conversations she had with those groups in Cambodia, it began to be apparent that to give freedom and independence a wheelchair needs to be customised to the body, lifestyle and environment of the wheelchair user, but with traditional design and manufacture and distribution, that level of customizing comes for a price. The average salary in Cambodia is about 950-dollars. That might explain why wheelchair users there weren't able to obtain customised wheelchairs. They have limited choice and control over their wheelchairs and the diagram below shows a typical customer journey. You might work with a wheelchair therapist who in the majority of cases will purchase a wheelchair from a retailer and they in turn have gone to a manufacturer and they have worked with a designer, so the wheelchair user never comes in contact with the designer and rarely comes in contact with the manufacturer or the retailer. Across the world 65 million people require a wheelchair but eight out of ten cannot access one that meets their needs. That amounts to 52 million people. Having identified the problem, we started to notice other organisations doing interesting things particularly in the area of prosthetics. E-N ABLE is one Rachael came across in Jordan.

They crowd source the design and manufacturing, so they establish a basic principle for designing prosthetic hand and share that with anyone anywhere in the world online and then they connect people to local manufacturers in their area able to manufacture prosthetic hand and they primarily use 3D printing. We also got in touch with Paul, Denise, and Autodesk in Germany. Denise is the first ever athlete to come Pete with a prosthetic. It took less time to produce this and a lot less. Another organisation are open bionics.

They take a similar approach but combine it with robotics. They can create a robotic arm in 42 hours for 3,000 pound which is it still sounds like a lot, but it is around 30 times less than comparable prosthetics on the market and they recently won the James Dyson award. This left us with this question, what would happen if we disrupt the design manufacture and distribution of wheelchairs with user innovation, open source design, and distributes man ewe fracture, and what would happen if we developed a community of makers and people with wheelchairs who could be enabled to make customised wheelchairs. We were real inspired and we wanted to understand if there was potential for us to apply those developments, particularly around the technology to wheelchairs. For me the most exciting response was I'm not a

wheelchair user I wear my wheels. We found a wheelchair is an extension of your body. You wear it every day and like that pair of shoes it's something that you would not go out without and if you can have choice and control over the look and feel of that wheelchair, if it's something that feels part of you, then it's not a medical device, it's fashion or wearable tech, or a lifestyle project. I'm not a wheelchair user myself, but I was talking to my father who also wears glasses and when he was a kid he was prescribed glasses and had limited choice or control over what they looked like and his experience toward them as a child was different than mine. So we apply what has happened with eyeglasses to wheelchairs. Practical things. We started talking to wheelchair users and designers and makers about how can this work and how can we enable the greatest level of customization. We want them to be able to take elements they dislike and change that. What does that look like? The pictures on the presentation show some Lego blocks, which is probably the most identifiable modular design system there is and like Lego, we share that compatibility. At the end of the day, we want to take that process map I showed you earlier and change it so that the wheelchair user or wearer has the direct control over design, customizing. We think that the design libraries and making should always be open and free to access. We see a role for the service, yes it's a profession and there is a lot that goes into it, but also it's something that we think a bit like the presentation earlier like gait analysis, that we can use sensors to digitalise so the wheelchair user has more control over how they use that service and individuals will be able to select a design and customise it and send it to manufacturers to produce their design, and also workshop making events. So far we have had 120 people attended HackOnWheels and hack-a-thons. We have had the support of 150 different organisations and we've built a movement of 1,000 people who are directly involved with us through attending events and contacting and getting involved online and just providing their feedback and letting us know what they think is most important. We've a volunteer design team creating a modular system and building a library on wevolver. At the moment we are running a design brief for the RSA student design awards sponsored by the GDI design hub. We are hoping to have 300 designs submitted for the competition. They are the only student design awards that are accessible that anyone can enter regardless of their course that they are doing they just have to be in higher education. If you know any students looking to get involved we've two really great challenges you can ask me about afterwards. Together we are disrupting disabilities. This how you can get in touch if you want any further information after today. (Applause).

>> Thank you for that Molly, it's exciting what you're doing and the potential it can have around the world. Does anyone have questions for Molly? Yes, lady at the back. Can you just wait for the microphone.

>> This won't be a robust question like the last one. This is really exciting because in Pakistan we've no manufacturer of wheelchairs at all. Our rehab section is trying to develop willing and looking at light-weight wheelchairs do you have any contact with international committee of the Red Cross?

>> Not that I know of.

>> I will ask them. Thank you very much, really interesting. Thank you.

>> Any other questions? Question at the front.

>> Is there styles of wheelchairs that you're looking at? Have you looked at I'm thinking of my daughter's wheelchair which I think cost something like 16,000 dollars and has lots of bits and pieces rather than being a racing one, have you thought how that can be done?

>> We are open to all an we want to have that mix of motorised chair that have more structural support and more like Rachael's slick titanium chair she uses to climb mountains. It's being community led, so we run events to connect different people with different disabilities and different reasons they use a wheelchair and involve them and their carers in the design process, so at the moment because we are really quite new still, and light weight in terms of our resources we are reliant on the community to contribute and get involved which is another reason for promoting our way to get involves.

>> Very, very cool, indeed.

>> There is a question of this gentleman here in the striped top.

>> I'm Tom. I don't know much about wheelchairs but I was wondering depending on the level of customization you need, have you looked at the bike industry because with standard parts you can build your own bike.

>> That is what inspired us actually is thinking about how if I want to change something on my bike it's quite easy for me to just order a replacement seat online and drop into a bike workshop. I took a wheelchair that I'm working on at the moment to a local bike shop recently and I needed a particular type of tool. I was talking to them about the wheels and they had all the right tools but not quite all the right parts and nothing was quite compatible, and that customer experience that you have when you have a bike that's kind of what we want the customer journey an experience to be like for wheelchair users and that is a really cool project thinking about 3D printing and manufacturing, there is an open source 3D bike that you can make. That is a great comment and something that we're looking at.

>> Does anybody have any questions for Molly? Lady right at the back.

>> Great presentation. I just wanted to say it's fantastic what you're doing. I wondered if you want to say anything about make a space and their lack of accessibility.

>> Yeah, this is something we see as being a barrier particularly when we get further down the line towards having an online platform that people can use. At the moment we are working in a make a space in London, which is great because an open workshop there is all the tools there and everything is there for me to be able to adapt this wheelchair, but we recently had an exhibition and they are fantastic and big on accessibility, and they built a toilet, but they had an exhibition and the machines I can't actually 3D print something by myself at this level and the kind of things that we've where you can't get close to a table, so

down the line we think that's an area we are looking into in terms of collaborations and partnerships and making this industry a lot more disability friendly and aware and trying to address those issues further on in the planning stages. The opportunity there is that the concept of make-a-space, maybe a show of hand of what knows what it is? Okay. But definitely like a year or two ago nobody would have had a clue, so an opportunity there is this is still quite new and the make a space and distribution and manufacturing movement is still growing so we can really embed some of these issues and awarenesses of disability access right in at the beginning.

>> Anymore questions for Molly? A question from the lady right in the middle she is just standing.

>> Suzanne from Denmark. I work with small startup companies, a great presentation and idea. Just wondering how are you deal with the regulatory issues when you change the product, who has the responsibility?

>> Kind of like hide behind -- online library at the moment is on revolver while it is accessible and can access the designs we don't promote it for that reason because as we grow we need to look into some of those issues to be quite honest. Actually one of the opportunities here is in terms of being user-led with user-led design if you're taking the product and developing it for your purposes yourself, this already happens, please adapt their wheelchairs and one of our hack-a-athons we had he was talking about how he got his first wheelchair in 1973 and prior to being paralysed and having to use a wheelchair, he had those motorbikes and so he just took his wheelchair to his motorbike workshop and took it apart and adapted it and made it cooler and something he could do marathons in tanned play basketball and do marathons. You've got to have something that's livable. Someone gave me a stats that rather irritatingly forgotten last night about the number of wheelchairs discarded because they are given and they are not comfortable and that is an enormous waste, so we are hoping to tackle some of those things and drive it from a user-led perspective.

>> Does anybody have any additional questions for any of the other speakers before I invite them back on stage. If you could put your hand up if you do have any other speakers. I'm taking that stern silence as a no. If you've got no other questions or no other comments, then I thank you very much for coming and I will end the session there. I'm sure the speakers will be around if you want to come and approach them individually afterwards if you have any questions for them, so thanks very much for coming and I'm encouraging you to go to the next session on at 3:00. Thank you very much. (Applause).