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Parallel C Lowther
Independence**

>>: Okay, I am going to suggest we make a start. Good afternoon everybody. Welcome to parallel session C. My name is Ron. I am the moderator at the workshop this afternoon. I have four presentations all on the topic of independence, obviously which is the theme of this afternoon's break out sessions. Our first speaker this afternoon is Gavin, who is the CEO and founder of neat box and Gavin will be speaking to us about how neat box utilises existing technology to create innovative and great solutions. Gavin all yours -- innovative and inventive solutions.

Gavin, all yours.

>>: Just check this is working. Excellent.

>>: Good afternoon, ladies and gentlemen thank you for attending this presentation. There is a very good chance that all of you will have a relationship with technology. My guess is that you are already aware of the accessibility features on I-Phone or Samsung and some of you may already be using applications and in your daily work but are these applications and the technology the remit of tech users oa lone or can (inaudible) influence the use of solutions. I hope to demonstrate today not only is it possible to feet into the development of new technologies in our industry but as the subject experts it is imperative that we are involved in this process.

>>: I had better actually start presenting. Insertion point at start I suppose that is me. Many of you will know that is voiceover functionality that is standard on I phones, certainly visually impaired people would be used to using that technology. It is standard. I will turn this one off now. I mention there that practitioners and problem holders certainly end users, other people that should have a responsibility to actually come up with solutions and the reason I say that is because technicians, academic Partners, Governmental agencies don't truly understand the lives that people with disability are living and the people who truly understand those lives are obviously the people who have a disability but also the practitioners who work with those people. Now I am not a techie. Although I have a technology company.

Speak into the microphone but also use a mouse. This was me for 18 years of my life. In the picture is me looking tanned in Scotland, that is an achievement itself but I was a guide dog mobility instructor. For 18 years I trained people how to use guide dogs. I loved it. It was the best job in the world, I would still be doing it had I not seen something I felt needed to be changed in the world I was living in. In the photograph there is a young chap with a guide dog, here in Edinburgh. He has arrive at a curb edge and waiting to cross the road. In Britain, I know it is different in different countries in the world. In Britain what we have to do is press a button, mate for a signal and then we cross the road. Worry can't even find this button, let alone press it and get back to where he needs to be prior to crossing the road. I liked walking around in my shorts and polo short. My life now is business suits and ties. I am happy to be here because I don't have to wear a tie. Pressing a button with a mobile phone so the button at the pedestrian crossing is pressed automatically when you get up the to crossing. This is technology started by somebody who understood the problem. I am not an academic. I don't have a degree I didn't go to further education but I did 18 years training people how to use guide dogs. When you live that world you see the problem that people have. The two pictures I have on the scene here are one of pedestrian crossing application which looks for the pedestrian crossing and then presses the button for you and the other is a customer services application which I will demonstrate a little bit later. So why did I come up with this solution. On the green now we have quite a few pictures of different pedestrian crossings and the challenges people have in interacting and pressing a button you suddenly look and say why are we not pressing a button from a distance. Why do we have to press a button manually. When we wall around with smart phones in our pockets. In the future we are going to be able to do this much more so why not do it now? Why not do it now. We did. We are now doing it in Edinburgh we have six of these crossings all activated by your mobile phone. We are the firsting the world to have done this and I am so proud to say there is one outside this conference centre and I will more than happily show people this are we have finished today so a a few photographs came up on the screen but to truly explain why it is very important we need to just have a little look further. This lady on the screen is coming up to a pedestrian crossing. She can't reach the button and I say to her how do you normally cross the road and she says I hold out my hand and wait for the traffic to stop. This is how she crosses the road on a daily basis. The car approaches the junction. The driver is coming up and he is seeing a green light and keeps going. Nancy is waiting for him to stop. It is actually more dangerous at a pedestrian crossing than it is at any other crossing because there are certain examples of how somebody is supposed to work. When you live this as a guide dog mobility instructor, a practitioner you think do I just let techies come up with the solution or do I find the solution myself. At the same time I working for blind dogs for the blind I set up a company had to put in my own funding and came up with a solution. The pedestrian crossing ap works on the I-Phone as I say we have eight or six crossings in Scotland also works on the apple watch and currently pushing forward with a situation where

the phone doesn't vibrate but previously the phone vibrated when the green man came on and the potential is to have a vibration on an apple watch as well. So the future or technology isn't the future, it is happening now but practitioners need to feed into that. You guys need to feed into that because techies will get it wrong and unless you talk to end users and also to the practitioners. This is a BBC video. With a very famous chap in this room.

>>: One of the difficulties I have with pedestrian crossing is sometimes getting close to the Paul. Very often very much to the side and difficult to reach. There is one that I use occasionally where you have almost got to go into the bushes at the side before you can reach the button. Being able to come up to the crossing without having to get close to the pole would be an advantage.

>>: When you approach this with your pocket working independently it will press the button for you.

>>: A company in Edinburgh called neat box. The invention was developed by a former guide dog instructor who realised how difficult it was for disabled people to press the button.

>>: It is really very simple, the person approaches the pedestrian crossing the mobile phone in their pocket and recognises the crossing and presses the button, the person waits for the audible signal and crosses the road. We install hardware that sends out a signal, mobile phone communicate with that that and it is all happening in the background.

>>: For someone blind like me who can see absolutely nothing. Big open space like this one can be very confusing particularly when you are trying to find the reception. It is hoped the same technology could alert staff if a disabled person needs help.

>>: Hi.

>>: Nice to meet you.

>>: That's fine.

>>: We install our beacons incite the entrance to these buildings. As soon as the person gets close to the beacon their phone interacts and then interacts with the reexception or the S customers service team so it is very simple they know the person has arrived.

>>: This is the first personalised pedestrian crossing in the world and it is here in Edinburgh. The challenge for Gavin is to persuade local authorities and businesses to install his technology.

>>: So we mentioned the customer services application there as well. It is currently being tested in beta and it is live in the Hilton hotel some of you might be staying in tonight. You download the application. You walk into the Hilton hotel, they know you have arrived, they approach you and they introduce themselves the way you want to be introduced and you can put in in advance in the phone what you need that day.

This can be used in any train, station airport we are hoping to install it all over the world. Pedestrian crossing we are going to be installing in Canada shortly and working with a company in Canada. We believe this particular product is at the very start of what is possible and if we just mention for a second

you are approaching a hospital door or the or here the door opens because you have download the application. No more waiting for the security guard to press the button. I am going to run out of time soon. It is the pedestrian crossing that is outside this very building. If you would like to test it we can go out any time today or tomorrow. I am very happy to talk to anybody who has an interest in having this kind of system in their own country as I say this is possible to be done anywhere. The technology we use is blue tooth low energy 4.0 which is beacon technology. Once again I am, us so incredibly proud to be here and to have had a chance to tell you about it. Please tell other delegates because it started in Scotland. It is Scottish. Thank you very much indeed. (Applause).

>>: Thank you Gavin. Are there any questions from delegates that they would like to put to Gavin. If you could indicate by raising your hand that would be great. We will bring a microphone to you. You will need to speak into the mike and here is my assistant.

>>: Hi, thank you very much for that presentation. I am, it is an interested question because I have been the product manager for a project in a shopping mall in Montreal to make it more inclusive for people with disabilities. We work with beacons. It was more at an academic level I was wondering what is required by the institutions that decide to install this?

>>: It is actually much more simple than you could possibly imagine. The applications, all of our applications are free we don't charge anything for the applications. The person just needs to have a Smartphone. In the future we will have other pieces of kit. Let's assume we were installing this in the Hilton hotel. We would install our piece of heart Mare, the heart work is done by the application. As far as we are concerned we want to as we say in this country stack them high and sell them low. We want this to be everywhere so we should charge an institution like who tell maybe £20 a month which is I don't know probably \$20 in his day and age. Twenty pounds a month would be enough for us to actually have that system fully inclusive and working throughout an entire year so really very low cost and very easy to set up.

>>: Thanks.

>>: Do we have any other questions. There is one further towards the back of the room?

>>: Hi. First of all I want to say thank you very much for coming up with this, it is a brilliant idea. What are the Scottish covered saying about it in regards to running it across Scotland having every Local Authority and every crossing.

>>: That is a brilliant question. I have been involved in the traffic industry for quite a while going along and talking to people and because of that I have had quite a lot of interest. Next Tuesday will be presenting this at the Rhodes Expo at Ingalstone. We have also been in talks with Transserve who cover all of the trunk roads in Scotland and we are going to be installing eight of these in Ingalstone which is a small town on the other side of Scotland which will turn the entire town into what somebody coined the phrase the other day instead of a smart city they call it a neat town and I quite like that because of my surname.

Scottish Government have been really positive. Still waiting for certification fit to be fully certified obviously when you do things in public infrastructure you have to be. Because so many people are wanting trials we can do the trials easily so Edinburgh already has several. RBC Head Office has one. One outside the Scottish Parliament. 2 outside the IPA vision. One outside the international conference centre here. 8 in lags TfL Transport for London will be installing one in London very shortly and hopefully we will have 12 fingers crossing the British University of British Columbia in the New Year. Thank you and I would love to talk to anybody afterwards.

>>: Do we have any other questions for Gavin. In that case thank you Gavin.

>>: (Applause).

>>: Perhaps I should have mentioned at the start if any of our delegates are interested in receiving copies of the slides from this afternoon's workshop electronically at the end of the session come and leave your e-mail address with me and we will mail them out to you all of the slides from all of our presenters. Okay. If I could call Delfine to the tech turn. Delfine is from the University of British Columbia. She is a post doctoral fellow and will be talking to us this afternoon about the well being at home of people with disabilities and their families.

>>: So thank you everyone for being here today. So the presentation of Gavin was I think great introduction to mine as well because it was talking about the interaction people with disability have with the environment and how it is important for them to reduce their level of disability according to the social model of disabilities, the environments that create that disability so if we can improve the environment we can reduce in fact increase the social participation of people with disabilities and I think it is the goal of an inclusive society so tot I am presenting my project which was my PhD projects, in Montreal and Canada and Quebec and so it is about well being at home of people with disability but as well of their family members because we know that care givers, family members people with disability interact with people and those people also are touch or concerned by accessibility universal designs and that is why we included them in that study. So well being at home so for people with and without disability home is a place to fulfil and develop needs but as well as family or social needs and it is also a place to promote an active and independent role in the community. It is often described as the first environment of the person the home is not accessible or if the person cannot fulfil his complete needs at home it is hard are that to go outside and in the public environment and enjoy a social life or a social participation and it is a well being at home is an internationally recognised as a right by the convention of the right of person with disabilities from the UN but despite its importance of homing people in the life of people with and without disabilities there is few studies in the (inaudible) mostly related to home and when you look on the disability literature there is not a lot said about home so that is why we focus on this on the studies and as well as you will see we use the model to try to broaden the spectrum of needs looking at, because often we look at the

studies, studies look at the physical needs and are going to make levels so the person can conduct basically like feeding themselves or getting dressed but we know that human being is more than that and so we will try to cover a larger spectrum of needs as you will see so that is the model that we will use for that study so the psycho environmental potential model. Still for the organisation on environments we applied it to the residential environment because we think it was comprehensive and it was covering a lot of the needs which have been identified as important in the literature so to cover them I will go a bit rapidly but I will do my best. Shelter and security will be seen as you may recognise, close to the (inaudible) of needs and psychology so shelter and security will be the most basic needs so its protection from physical environment and threats to the personal well being butcles includes psychological safe this feeling safe in your home not only feeling protected from the environment. Social contacts facilitation (inaudible) interpersonal contact or privacy in the home we want to receive our guests and friends but we also want to have moment of privacy which your family or friends when you are with your family so you understand the context here so single identification is information about the values, preference of goals of the users so how the environment provides an idea of who you are. Who the family is tasked instrumentality, the most needs I would say so quality of equipment and spatial arrangements for the accomplishment of specific tasks. A could example here is for example in a kitchen having the cart board good height or having (cupboard) a room where the person can speak well it is really to the environment that fits for the task that has been put in. Pleasure, it is just the ratification of being in a setting so it is all about aesthetics, comfort, beauty and all related needs and growth is the final one would be the highest one in the hierarchy according to that model so it is low end services to learn things about the world and themselves, so it is all about personal growth but as well as go within your interaction with the environments. So the objective of our projects and I have to say this is just one part of our biggest project that we conducted. If you are interested or want to know more we published couple of papers so far on the different dimensions. This one is not published yet but there is other ones so looking at the priorities in the house adaptation specifically. We also covered that and we have another one looking at family functioning, so different things. So here I will present how. In fact what is the relation between the house and the house as the physical characteristics an the well being which is psychological needs as I present. So globally and for a specific places as -- so as a research so we met with people from Quebec in Canada. It was people with spinal cord injuries so yes that is important to say I think because spinal cord injury people are people with disability later in their life so they are not born with disability so we would not say that it represented all kinds of disabilities but I think because of their interaction with the environment it is kind of confronted and they have to develop a new relation because of their new disability we thought it was an interesting group to study and so it was mostly men, the main age was 45. They were in couples they had to live with someone so it was a little bit difficult for the recruitment because as maybe you know people with spinal

cord injury which induced a lot of divorce and separation so it was hard for the recruitment but we end up having 35 families and we are really glad about that and we had people with paraplegia so we can move the upper part of their body only but we also had half of the sample was living with tetraplegia with higher level or severe disability and in the house we mostly had owner of their house so maybe it is hard to compare to people with rent and have maybe less power of how to transform their environment and we are really conscious of that. But it was and it was mostly people who move in a new house because they had this injury. So it was interviews, qualitative interviews simultaneously so with another person was going with me to meet the people and we have closes and open ended questions but most questions was about what is the place where you can have a social contacts and why. What is the place where you feel you can grow and you can learn about things and why? And explain how so the results are coming from hose series of questions but we also look at what was a barrier or what was imparing well being of people with disability in their home and of their family member as well. So what came out is that which is great, it is that eight places in the home so on ten possible places were considered as favourable to well being so we can say people had positive experience of different places in their house so for all the people mostly the living room in the house as a whole was positive for them. For people with spine cord injury bedroom as a particular place. I think we can understand why because spinal cord injury needs a lot of personal care and they want to have their privacy and their intimacy related to to those and it is also a place they spent a lot of times. Other studies show it is the space they spent most times in the house that is why it is really important in their perceptions and related that was the kitchen really favourable to their wellbeings and they identified different objects but I want to pinpoint the computer was named by everyone in all the sample as something that was important for their well being. Delivered the technology that is important in everybody's life so we ask people as I mentioned why places are contributing to your well being so mostly people talk about real I this. Having a place their own they can call their own on which they have control which is important because a lot of people feel they lose a lot of control when they become disabled. They also talk about using and developing their skills and I will come back to that because I think it is really important things and activities with others as well so they want to be able to share their space with the others and do things for them. For people with spinal cord injury it was also convenient for work and ledger and being able to learn about the world and it was a lot related to the computer and for a related this side and privacy was an important aspect. When we ask about what was not favourable for well being or less favourable there was for half of the people they say there was no place for objects. Maybe we had a sample really good house. We don't know exactly how to explain it was like solo because we know there is barriers but that was our participants shared must but for people in general so the kitchen was also the most unfavourple place of well being so it was a great place but it also has negative aspects and that is what is important with the model we use is that the same place can be as positive aspects and negative

aspects. Nothing is black and white so it is a grey nuance there. For people with spinal cord injury the basement was not a good place for them mostly because it didn't have access to it because I don't know about Scotland, but in Canada normally they will give money for adopting one floor so if a concern hat two floors the base went is not transformed, nothing to access it and for relatives sometimes it was all the names as unfavourable but mostly related to safety and our sample there was a lot of women that was related to the people with spine cord injury. They cannot notice now their husband Orson has a spine cord injury they felt less safe. They were not necessarily able to help them if something happened so that was related to that. So the lack of convenience for moving around, the basic accessibility of just being able to move around in a wheelchair was the thing that was the most important and the lack of convenience for daily living activities for people with spine court injuries was also fully important and for relatives it was the psychological and physical investment so what is interesting there is for them the disability trends from the user trends for everyone but it also mean in most of those families some places were not used any more and for family members if it was important it means their house, come part of their house was not their home any more because nobody was going there. So that is something interesting that came up there. We also look at how each specific place distributes to well being. We don't have time for me to cover all that. But what is important here is that often the space like here is the example of the kitchen, the kitchen was light or favourable for the reason it should be. What I mean with that is that people liked it because it was an open space, they could do activities with order. It was convenient to develop new skills to communicate. The equipment was easy to each. One aspect of for a relative but a kitchen should be a place, it is common place in a house where you are to share with others to cook so it was really like they liked the place where fulfilled the function it has meant to be and the same things it didn't like the house when it was not fulfilling, the case when it was not fulfilling the space. The function it needs to be so the same thing you can see almost a contrary of what you see as being favourable that is unfavourable to limit the development of skills inadequate underneath, lack of convenience for academic activities and you have an example of a quote of that share with her us her experience. In conclusion what do we learn from well being at home? From our example and again we are not necessarily representative of all the people living with disability. We would never say something like that. But our simple positive experience but that experience was also multi-faceted, it covers a lot of needs and that was the important part of being at home. The negative experience was more limited, people talk mostly about tact instrumentality answer safety but as I underlined a family talked about the effect on their single, the importance of specialisation of room and the experience we compare the experience of people with SC I and their relative and their experience was relatively similar but we saw the the disability was impacting differently. People with disability. I will go to that right now. Because this is kind of like the biggest conclusion we find so for everyone, social contacts are the importance so at this where they are similar. Everybody mentioned that

they wanted to control the interaction but also have interaction at home and one of the big reasons is that they mentioned that the other their friends houses is not accessible. Their parents house is not accessible so being able to receive people in their house was really important and also for me what it is, I was surprised is this morning there was a speech from a presenter, Michael Fox, and working and saying in Australia they have all those laws about accessibility but housing was the last target in access we and I understand it is important people go outside here in public. But here we realise socialisation the home is really important so I think it was for me it was really surprising when you just present that when you no it is so important and for people with disabilities so (inaudible) instrumentality. Basic things as I presented earlier are really important and the picture you see below it is from our participants so we have for example this music studio on the right so it was one of our participants who was a wrapper and he was able having all adapted to be working and be creative because the environment was usable and also shows that it is it also brings back the house is central for social participation. As it said at the beginning it is a central environment, the first environment and if this environment is well adapted then the person can easily or more easily go out and participate in the rest of the society and as well I think this applies to this example here of the studio but there is related to being able to go out of your house as you can see with the picture in the middle the ramp that has been constructed and as I understand for the relatives the importance of (inaudible) occasion that was restricted so they felt that their home was not reflecting who they are any more and I think this is important in adaptation because yes we consider the people, the person with disabilities needs and it is really important but they are living with question else I think in the development of that application doesn't look like a hospital. Maybe we can put bars or bed, a bed move up and down there is a need to look like a hospital bed and think this is something it came up more for people the relatives but I think it is also important for the people with disabilities there so that is what I wanted to share with you today. Thank you very much. (Applause).

>>: Thank you Delfine, are there any questions for delegates for Delfine before she leaves the stage.

>>: Gavin. Thank you did you do a study as to the types of technology people were -- sorry if I have asked you the wrong question.

>>: Not at all. Totally an it is why I was saying at the beginning we covered a lot of things. Yes when we looked at the adaptation in the home we asked them what kind of technology they were using but it is okay, it is going to sound funny, research is always wrong we finished at the data collection in 2009 and at that time technology was yes there was the beginning of environmental control but it was not that much like aps were not used so I think it would be different now but I am just --

>>: That would be interesting see a graph as to how it is going to do.

>>: It is contributing a lot the technology. As mentioned at this something that came out it has to be user developed. Sometimes people develop things in the technology for a house and no one uses it.

>>: It is very true on social media the people using technology alive on social media without people with disabilities being involved. They are all talking to each other and that is the movement that is happening right now.

>>: Absolutely.

>>: I think we have another question on this site of the room.

>>: I was just wondering to what degree, obviously everybody in the sample was post injury. Had they all moved to accessible accommodation or had their accommodation extensively modified or was it a mix.

>>: It was a mix. We had half of our sample that like brand new home. Fully accessible. They were and that is also why I was really underlying that it is people with spinal cord injury because the most reason for spinal cord is car accident or work accident and you are covered. In Canada they are covered and they cover your home adaptation. Those people were by the way have great transformation but half of the sample was not having like. They had small changes, supposedly for the bedroom.

>>: I am also from Canada and home renovations are only covered depending on the source of your injury. So it is very different depending on the source of it. Did you in your findings did you differentiate between satisfaction of those who had modifications.

>>: Yes, we did and like we did statistical comparison. There was no significant difference because what I am saying is like for example social contact was important for everyone but there is a paper in the Canadian journal professional therapy we published and we looked at the difference between satisfaction and unsatisfied and satisfied people with home modification and there was not that much difference according to the needs. There was more difference or no that is not true there was difference on the safety level. Those who had modified homes, way safer.

>>: Okay. Do we have any other questions. In which case thank you again Delfine and we will move on to our next speaker this afternoon. Mirca from Finland the rehabilitation foundation in Finland will speak to us this afternoon on the topic of migrant children with disabilities and their children within the Finnish welfare system.

>>: Thank you. Very happy to be here. My subject is integrating families with disabled children within the Finnish public health services and this is a research project done together with my colleague senior researcher she couldn't be here today but I am here to present to you.

This presentation.

First I am going through a little bit of the background to give you some context. The Finnish public welfare services have been constructed during a long period of time and they are mainly constructed for citizens with certain kinds of needs and certain kind of legal and cultural and so as Italian background. However since 1990s the immigration has increased a lot, even in the last couple of years and that means that we have new people with diverse backgrounds using our public services and they also have a sort of also legislation

currently is equal access to public services for them. However, this doesn't always happen in practice due to the fact that the services and credit people do not fit together very well and this incompatibility is quite problematic for both sides both for the credit people and for the professionals working in the services and the problem is tackled by promoting integration and by integration we understand adapting integrated people to fit the services. Not the other way around so not modifying the services to fit the in credit people and there are a number of projects and actors promoting integration of integrated people in Finland and there are a number of actors promoting inclusion of disabled people as well and one of these actors is Wemloss foundation and they carry out project that was aimed at developing in decoration work done with within the credit families with children with disabilities and integration that worked for the project. She worked there for like 2 years and she worked with the then client families who had the emigrated to Finland with a child or children with special needs. And her task was to promote integration by offering support and guidance for the families but also supporting professionals working with the families. And then we come to our research days which was work diaries like this integration adviser. She kept like a diary from her work with the families. She documented their starting situation, contacts made and needs expressed by the families and as well the support information, advice and help provided for the families and professionals as well and we analysed the work diaries by using narrative analysis and that means that we collected descriptions of cases and events and used them to construct two stories that concern fitting together professionals working in popular services and integrated families with disabled children and a lot of these stories share the same structure and story line so in the beginning it is justified by the services and families need to be visited together so rely integration adviser work is needed, what is the reason behind that and the middle part reveals to me integration advice in her work. In the end it is reported what needs to be achieved before integration adviser is able to detach herself from the work she does. The stories differ in two perspectives. In the first story integration adviser offers support to the families and then in the other story the support is of the professionals and I am going to read you the stories soon. I am just reminding you that these are very extreme examples and we named the first story a conventional story and it is from families' perspective. Integrated children with their families cannot cope with everyday life and need help and support integrating to Finnish society. Parents might be illiterate or their knowledge of Finnish language is limited. They might have no understanding of the service system and they don't understand the information taken from service providers. They make the use of the services problematic. The integration adviser supplies the information of the service providers for the families. She takes care of the affairs and teaches them how to use services. She shares information and creation of activities for children. Corrects misconceptions regarding income support, participates meetings, sends text messages to remind about doctor's appointment. Guides how to deal with broken mobility equipment. Speaks to the family at home and then considers the patients to deal with social worker by themselves among other things and it

is possible for the integration advisers to detach herself from the work with the families when I literate parents have learned to read and write or parents have learnt English enough to be able to access the system independently. They are able to find out solutions for their problems and know how to take care of things over the phone and in writing online. Parents are healthy and they have enough resources to take care of a child with special needs. Families are aware of their rights and responsibilities. They are determined to find solutions for possible problems and nowhere to seek help in case of need.

So that was the first one and the second story is called reformistic story. That is from the professionals' point of view. Professionals working do not know how to manage the complex situation of integrated families with disabled children and need external support for their work. They don't know how to support families with I literate parents or with limited proficiency and are not able to provide guidance and advice to families understandably and they don't take into account families need for personal services and the integration adviser takes care of things on the balance on behalf of the professionals and teaches them how to manage things by themselves. Also enquiries, situations of the families, information from professionals to the -- and advice is for professionals to use plain language and other supportive needs to facilitate the interaction with all the families. The integration adviser also instructions professionals to provide information and advice to families regarding exceptions from payments, therapies, medication, assistive tools and holidays activities taking into account a possible need for personal customer service. And it is possible for the integration adviser to detach herself from the work with professionals when professionals have learnt different kind of ways to manage, Finnish skills and social background of families. Professionals use family mentioned and comprehensive approach and if they have the means to facilitation communication with families they are asking you to guide questions and give the add VAT information for the families. Understanding they might have difficulties in observing their honest and when needed to generate personal support for the family. And how we see it is that the conventional story is sort of like a finished model story here so with the concept of the story we refer to stories that where people behave in a certain way in a certain cultural community so it is sort of like expected that families integrate fully or at least in some to be able to use the public services independently and this is in the spirit of the law as well and a story itself is (inaudible) and it is very familiar but there are some ... however the conventional stories also shackling needed the fact it is influenced by methodological nationalism and it is considered self-evident that Finnish services remain unchanged and credit people that need to adapt to fit the services and the reformistic stories challenge is this. It is distanced from methodological nationalism and it is considered instead that the welfare services are for everyone and by everyone might be a little bit different than it was before because of the increased integration but from this perspective the appropriate way to solve the income, the ability between services and integrated people is to modify the services to fit the integrated people. And to conclude we might want to ask what kind of stories we want to tell about

Finnish society and public welfare services in the future. Integration of integrated people is important and valuable however we cannot depend on the level of integration when it comes to these services. It is unsustainable basis, especially for people for groups like families with disabled children. Many are in immediate need upon arrival. Many, some may fully integrate, they may never learn Finnish language enough to be able to navigate the service system so there will always be someone who is in the need of assistance and help and services need to be open and accessible for all so we need to construct a new model story which does not follow either of the previous ones. It is situated somewhere in between so the need for the integration services remains but the change in professional work practices is also required.

>>: Thank you. (Applause).

>>: Thank you very much. Are there questions from delegates. If you could indicate by raising your hand. Am I missing. In that case, thank you very much. Our final speaker this afternoon is Dana Corfield, who is the founder and executive Director of equip kids international in Peru and Dana will be talking to us about children with disabilities in the global south, barriers to survival participation and education.

>>: Thank you, I am going to put on my timer because I will run out of time in my first few slides if I am not careful. Just a little bit about myself really quick I do run an organisation that works with kids I disabilities and their families in Peru something I have done for the last 17 years and we work in the south of Peru or also Uh in other areas and to a limited extent in other countries. We work at a really grass roots level one on one with families but also a lot with community based rehabilitation programmes and with schools community groups and parent groups and so on so I actually live in Peru for more than 10 years. 11, 12, years of that time and for the last 5 years or so I have been based back in Toronto done by masters working on my PhD in critical disability studies related to my ongoing work in Peru very much involve in the work on Peru. Now back in Toronto equipment for us kids Canadian but run out of Peru. To what I am going to talk about are what I see as some of the major gaps in, literature policy and R programming when it comes to kids with disabilities and for anyone not familiar with that term really is a newer term to talk about what we used to call developing countries or previously third world countries. I am going to try and I will be going over quite quickly what I consider major issues but I am happy to talk with anyone more sensibly after. When we are looking at gaps if we look at what is currently on the agenda and everyone I look at this I am talking about both in terms of the academic agenda and the literature that is out there. Also policy and programming. We all know those should all be directly linked and speaking to each other. The major issue here is there is a considerable disconnect so looking at policy as well as academics a quick scoping study of even with disabilities in the global south shows that most articles as well as policy papers et cetera are still relevant to biomedical information things such as prevalence certain statistical information about disability. Now that is not to say that we have good information statistically about children with disabilities on the global scale or in the global south specifically quite to the contrary.

Although of the few papers there are a lot of them do focus on this. They are often smaller studies and reiterate in the facts we lack a lot lot of good data and it is not comparable one study to another. Of course you get a lot of information with regards to children and education quite understandably and particularly inclusive education and another significant portion of the studies or the papers are about the burden of having a child with disability on families. So there is a lot about the stress of having a child with a disability for families. Families perception of disability different cultural context and then you get a smattering of other sort of ideas, things related to disability and disaster which we have here which is quite relevant and we talk about it in the context of the global north and south things to do with disability recreation I know this goes on to a lesser extent. So really what I am going to talk about is what I think is missing both based on my experience and those of some colleagues around the world but also based on the very limited literature and statistics that we have and one thing we need to look at is the demographics of children with disabilities because of course they are very, very different than the demographics of adults with disabilities and that is true in the global south as well as the north but I would say too much more extreme extent in the south. When we look at. Children with disability am I not going to put numbers up here because there are so many different numbers out there but there are some trends we certainly do see. The most common disabilities are intellectual disabilities and in the prevalence rates we have seen anywhere from looking at the global south it is even greater but from sort of two to 12 children per thousand so about one per cent or a little less and studies in the global south tend to show that about one and a half times as many children in the global south have an intellectual disability as compared to the north. Cerebral palsy and I will talk about cerebral palsy in particular. In Peru I can a most countries of the global south it is the most common childhood disability we see and the prevalence rates in our experience and statistical data that is available is usually two to five times higher than what you would find in countries like the UK or Canada for example and that is important for lots of reasons that I will come to and sensory disabilities are also a significant proportion two to three children roughly is the estimate per thousand with significant hearing impairment or visual impairment and just to give you the range to go back for cerebral palsy. In Canada or the UK for example two to three children per thousand is considered quite typical for the prevalence of cerebral palsy which is just for those not familiar with it is a physical disability that is the result of brain damage or before during or shortly after birth for children. So in countries of the global north it tends to be two to three not per cent but per thousand children and countries of the global south like Peru often between five and 12 children and there are studies that have an upward prevalence and I think the most important part to really recognise and that is not talked about enough or at all is the fact that most children with disabilities that we see in Peru and also colleagues that we have taught to sensibly in other parts of the world simply don't survive until adulthood. These kids aren't being counted. We have I will go back to some of the prevalence but based on our experience in

Peru for example most people who work at the grass roots level and you need to be working in that area for a significant number of years to see these trends generally speaking but for example in my particular work in Peru we work with each year about 100 to 200 new children with disabilities. The spread of those have cerebral palsy although there is quite a wide range of disabilities and when we go into a community or an area for every hundred children with cerebral palsy that we identify and family we begin to work with we can only identify about two or three adults with cerebral palsy. Also we provide wheelchairs to usually 50 to 80 children with disabilities. For those families we meet with them find out their needs measure the children and it takes about nine months before we can get the appropriate wheelchair to the appropriate child and every year 8050 to 80 children that we see nine months later when the wheelchair arrives usually on the low end it has been two children. On the high end it has been up to a dozen of 80 children have died just within the 9-month period so it is really really significant high rates. There is some statistical data out there but it is hiding. This is not the kind of thing people have looked at specifically yet but there are areas where you can look and find and prevalence rates of certain disabilities during childhood and then compare them to adult hood so for example in Peru some years ago, about 10 years ago with some other statistical data that was run they it was actually just in the area of southern Peru but they looked at the incidence and prevalence of intellectual disability and for children the prevalence was eight in 1,000 children hat an intellectual disability but for adults it was only one in a thousand so we have to ask what has happened to the rest of those children who were to become adults. There is also information coming from Bolivia specific to cerebral palsy where it shows again less than one heard of the prevalence in adults as there is in children. Other statistical data from South Africa and south east Asia as well as a few meta analysis have been done around the world show really very significant decrease and prevalence of disabilities that are not progressing life threatening but there are far fewer adults with those disabilities than children and that should not be the case. So a few quick things. Other important things to look at. Of course we always talk about education which is really important. Quite often stated within the global south considered less than 10 per cent of children with disabilities go to school. I would say in many environments even quite generous certainly it is the case in Peru. But we also need to look at the quality of education. In Peru when I first started one or two per cent of children with disabilities going to school. Now it is up to about 12 which is much much better although most of those children are just occupying seats because there is absolutely no support. They have been ate let in the door but that is as far as it goes. We need to talk about quality and who goes to school because it really is quite particular and I think this is seen in many countries around the world. Speaking quite plainly in Peru you can go to school if you can wall and tall and I don't mean in an inclusive setting but to the special education school you can only go if you can walk and tall and hat is really significant because as I will point out most of the children with disabilities cannot walk and/or talk or at least certainly most cannot talk and many not just cannot wall but

have no other means of mobility to get to school to start with and so when we look at communication I think there is another area that has really got got the attention it deserves and is so superimportant because communication really is perhaps I would say the ultimate right and need of a person and if you don't have a reliable means of communication I don't see how a child or an adult could access their rights or really be an active participant in their own life and when we look at significant communication difficulties essentially what I am talking about are children who can speak so that other people can understand them and in our experience and there is some other data out there as well although it is very limited more than half of children with disabilities in Peru and Latin America have significant communication difficulties so they can't speak essentially and this is not just because of cerebral palsy. For people who work with that population it is considered quite common and indeed the kids we work with because only one to 2 per cent of children and families have access to any kind of therapy or support services. Probably 90, over 95 per cent of the children with cerebral palsy we see do not speak and do not have access to another form of communication but it is also deaf children. By and large deaf children are not talked sign language and then they don't go to school. They don't learn to read or write so they are lacking of means of communication. Many children with intellectual disabilities such as Down's Syndrome they also don't receive any support and most of the children that I know with Down's Syndrome for example in Peru never learn to speak and many of these children, certainly the deaf kids, kids with intellectual disabilities many kids with cerebral palsy could learn to speak and the other should all be provided with some form of communication. There are lots of very simple means of augmentative and alternative communication that are very easy to implement in a very low income context but it is not really being addressed in terms of mobility difficulties of course those are primarily the kids with physical disabilities and we know that most adults with disabilities in the global south don't get the mobility equipment they need. Most don't get a wheelchair or an appropriate one and the situation is much much worse in the context of the global south. Very few if any governments reliably provide paediatric wheelchairs to children who need them, for example in Peru they are not made or provided and so it is very, very difficult to obtain them so even if a family wanted to send a child to school which most do, even if the school was open to receiving children with disabilities once they are big than three or four or five can be easily carried they are not getting there because there is no way to get out of the house and nowhere to put them. Those few children who are in school lying down on a mat in the corner of the room and that is not how one should access education. In terms of how many families receive non-familian support and I think that is important to say because in many of these different cultural contexts there is even more family support than we would have in a country like Canada because the cultures are less based on independence and more on family and/or community depending where we are working so there can be quite a lot of familial support but there is very little or no additional support so the vast majority of these

families have never had access to any kind of support or services, certainly not economic, not assistive technology, any of those things that we have come to appreciate and looking at families priorities this is based quickly on both my experience and also on my masters thesis looked at to some extent and my PhD dissertation looking at it in some part. Family priorities are really quite different than what is being given to them. There are some really basic things we are missing. One is information. Most families have no basic information about their child's disability and how they can appropriately support them at home so we often have families saying we just don't know what to do they are not like other children as they would say. Where you know what to do and so we just don't know what to do with them and they are hungry with information. It is very important for things such as feeding for example cerebral palsy being the most prevalent childhood disability in Peru there was a study showed over 80 per cent of kids with CP had severe to extreme malnutrition and that was for some reasons quite easy to fix in terms of feeding and how parents can go about feeding their children. It is also important to say that not only have families not receive information from for example the medical establishment or support services but the vast majority of families have never met another family with a child with a disability, certainly not a child with a disability similar to theirs so they haven't had that opportunity to share information that might otherwise happen and does happen and is very, very important when they are brought together. Education of course is important to families. They do want their kids to get an education. Part of it is academics. Part of it as they see it as somewhere they may actually get some therapy and another part is just getting them out of the house because most of these kids don't go to school. They are home all day and they need someone at home to care for them all day so that means that one adult in the family needs to stay home and care for the children in contexts where generally speaking two parents usually need to be working. Of course not all the families we work with are families living in poverty but a lot of them are. The vast majority of them are so they are already struggling. Support again is non-familial support. I know there have been some, the beginning of some income support in places like India and Ecuador that are trying pilot testing providing some income support to families with disabilities and they are talking about starting something similar in Peru and of course there is social acceptance which is just having the kids part of the community and dealing with the stigma and I should say there is stigma in all countries. We certainly have a stigma around disability in Canada about how productive or interdependent or not independent you are. Stigma gets a bit of a bad rap in the global south because we talked about it so much for so long and put a lot of the blame on stigma. Stigma is important there but not in all contexts. For example in the Peruvian context children with deafness, for example, children who are deaf, there is very little stigma around that so they can be very well socially educated but they don't get a good education, they don't have a reliable means of communication and there are lots of other issues. So that can be an issue but it is not necessarily. Why the discrepancy, real quick what is currently on the agenda and what I think the reality really is and clearly

a lot of it is just lack of awareness and understanding and that happens on lots of levels. Certainly at the academic level and as well as the policy level and also with disabled people's organisations, BPOs because increasingly we have been working with them. When I say we I don't necessarily mean my own organisation; that is also true but in academia and policy making circles. That is really really important but it is also true the demographics between the adults who run DPOs and the vast majority of families and children with disabilities are very, very different so often people who are running local disabled people's organisations aren't themselves themselves aware of the situation for children with disabilities and they families at a more grass roots level and it is also important as I said to note that parents are themselves so overwhelmed and OFN so isolated having not met other families yet that they haven't really been in a position to organise themselves and so they haven't been a resource that people have gone to yet. I shouldn't say just parents I should say families because it is not just parents looking after these children so I think there has been a dearth of information in academic and policy circles which is important because it shouldn't be his way but I have been told in meeting such as this before because the research is not territories not a problem and that is clearly not the case,. It is hard to get to and it is something that propagates itself because these kids are quite literally without a voice. Many are not surviving and many can't speak. You don't need to speak but they don't have another reliable means of communication either so it is a situation that has sort of been propagating itself I think and within that dearth of information we have had the agenda from the global north adopted in the global south and we are looking at things that are very important like recreation like inclusive education and things that are very important but to actually get there I think is going to my next slide we actually need to look at some the very basic things such as communication and mobility that we have mist because we can talk a lot about education and getting kids or schools to open up to kids. If the kids can't get there and the kids can't communicate it is not going to get us far in terms of meaningful progress. I think I have more than run over so I will stop right there. Thank you. (Applause).

>>: Thank you very much. Are there any questions that delegates would like to put to Dana. We have got somebody at the back of the room who will need a microphone, just bear with us a moment.

>>: Hi, that was really could and I can actually relate to that because I am from Indonesia and it is exactly like that. Kids with disabilities are not being taken care of and -- really good -- and it is a really sad reality especially from my country and our numbers are kind of almost the same so I can actually relate to that and my question is that what about the Government? Do you know that they are doing something? Is there any law? Is there any just anything from the Government?

>>: Within Peru like many countries it is quite interesting. There are actually a lot of good laws in Peru and recently -- good loss in Peru and two or 3 years ago they passed a very extensive wonderful disability law it is 60 pages long and pertains to absolutely everything and everything in line with the CRPD, very

progressive and very interesting it passed unanimously and very easily which is highly unusual in Peru but I think that is in part because people didn't really read it or understand it and see the population of people with disabilities as quite harmless, something they could pass and say it is a good thing and that is all we need to do but there are other things in there about needing to provide income security for example and things like that, if they really looked at it I am really surprised they would pass it in a Peruvian context but it is there. A lot pertaining to education and having to accept all children including those with disabilities into schools for probably 20 years but it is not enforced at all so the general experience is a family will take the child to the school and say want their child in school and the teachers downright refuse the child and that is the case in special education schools as well. I am not talking about an inclusive setting and in Peru they are pushing inclusive education which can be great and is great. It needs to be there but there is a lot more that needs to happen too.

>>: Thank you for that question. We have another question at the front of the room here. Just wait for the microphone.

>>: Hi there. It wasn't a surprise about deaf people not having an opportunity in education but what I am curious about is how are they communicating? Because I bet my bottom dollar there is communication happening. I am just wondering is it their own version of vernacular are they learning it from other deaf people. That is the question.

>>: Generally speak in in the family people get on quite well. They do have their own vernacular for basic things. Of course, both children and adults would have much more difficulty with anything more abstract. But for basic things they are doing quite well and kids out to play with other kids they manage quite well as well but anything that would be more abstract is a lot more difficult and it is hard for people, there isn't outside of Lima perhaps where there is a school for the deaf and there has been for many years, Lima being the capital there isn't really a deaf community in Peru so there isn't an opportunity to meet other deaf people and learn sign language and parents it wouldn't occur to them because they don't know how to learn sign language because there isn't a deaf community. We hope that will change and grow, but on the other side with a push for inclusive education what little bit of community that was forming is now dissipating because there that I worked in (inaudible) for quite a long time and there was a school for the deaf there, a very small one. It is a province of, I don't know, maybe 5,000,000 people and it was the only school for the deaf in all of the how the south of Peru so you are looking at 16,000,000, 15, 16,000,000 people and there was probably 20 or 30 kids there. However with the new push for inclusive education in Peru strangely to me this is also relevant for special education schools so any specialised special education schools like the school for the deaf can no longer cater to one population so now they have had to open up and become a special education school for all children and they are losing that specialisation and trying to work out how to work with children with all different kinds of disabilities now so in some ways we are

going backwards with this push that could be great. When I first saw the legislation for the inclusive education programme of course I got really excited. On paper it looks great but it is not how it is played out in part, in very, very large part because there has been zero dollars put behind it. A total of zero dollars.

>>: Do we have other questions for Dana. Okay. In that case thank you very much.

That brings this afternoon's workshop to an end. I would like to thank all of our speakers for what has been a genuinely international workshop. Thank you all very much for attending and as I mentioned earlier if anyone would like copies of the presentations e-mailed to them just come and leave an e-mail address with me and we will sort that out afterwards. Thanks very much everybody. (Applause)