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Parallel B Harris
Supported self help

>>CART PROVIDER: Captions will appear here.

>> Ladies and gentlemen, my name is Adrian I'm going to be moderating this session. I'm going to delay the start a couple of minutes, people finishing up their lunch. So we are going to have plenty of time. If you just bear with me for a couple of minutes.

>>Adrian: Okay good afternoon, I hope you enjoyed your lunch, I'm my name is Adrian, work for Scottish and UK government, we have four scheduled speakers. It is working now? Is it? Okay so um we have quite a lot of time for this session, what we are going to do is combine questions to the end, so we don't have questions for any of the speakers if you want to make a note of those come back at the end and go through those questions.

>> The gray educated background or qualifications in HR and also work for the charity as a support worker. Working with complex needs as well, with stigma with mental health. That includes mental health as well, some of the disabilities, it just creates independence, creates inclusion for all and gives society the chance to learn about each other as well which I think is really key and important to combine. It also creates income of freedom, because people are earning the money to work which enables them to go out and do the things they enjoy, but also spend time with friends and family, leads to positive life benefits as well. Can aid in depression, and links in creating a better life. Why step inside the minds of mental health, from my own experience, this is really important, I was educated in a mainstream education as a teenager I developed epilepsy so I sort of gone through the process of having disability. Didn't step away from epilepsy, but it was sort of like shouldn't talk about it or it shouldn't be seen or we stigmatize in regards to what it is like to be epileptic as well. Some of you may not see the disability, but it can be hidden as well and it can also create depression and the stigma from bullying and harassment that you can get from it is quite clear as well to maybe long-term and in the future. So last year I decided to go back to college, which was a good thing for me. I studied health and social care, during that process as well it triggered something back in my own childhood which then led me to have like a major depression outbreak and I

was quite poorly for some time, I was in the hospital for five-days, three of those days I was actually in a coma, so I am very lucky to be here. I am very grateful to be in HS, without them I wouldn't be standing here today and I think it is really key that we do need to support environments like that as well. They need us and we need them. Also not been afraid to discuss mental health because that's one of the key areas that people are so afraid to talk about it and then also when we look inside ourselves as well we see ourselves. We should be allowed to talk about it even if it is from religion, anything, we should be allowed to discuss that and we should be allowed to have the freedom and independence to talk about it as well. So disabilities matter, everybody matter, freedom to think and explore as well. And then why support and include disabilities or in my eyes abilities, I think anybody in this world that hasn't got abilities and we should be seeing that as a whole as well. Nothing will change, we need to influence now for the future and for the Societies we live in and also the children that have been educated at the moment, we need to look inside of that and everybody needs to be given that chance to express themselves. Employee help support and create well-being and then absence management as well in large businesses are at the moment, did have a background in HR and absence management for me was a big thing that I think needs improving. Only say that we can support more and give the people the things they need to get that support to stop in work. You need to provide support to individuals as individuals so it shouldn't always be processed driven. We should welcome discussion within the individual, change and monitor support is required and we should bring actions to prevent stigma and bullying and incorporate a safety net and freedom to do that. Put some masks on your chairs that I was going to use to say that if you wanted to put them on, I was just going to speak to you, so you get a kind of sense of how it feels to be a blind person within the room and how I would interact as well. I know a lot of people have got disabilities, but sometimes it is good to learn about other disabilities as well. And appreciate what other people go through. So for creating that safety net and absence management for me, I am quite strong in terms of how I feel about the NHS and the support they have given me and we should be doing it right and they have, a person centred approach, it should be based on the person and the individual, which I think we should bring into the workplace as well and so we should take on board the person not the process and we should listen, commit and assist anybody to improve and help individuals to learn and change and we should focus and guide that person to get to where they want to be. And with the Roger's approach as well, one size doesn't always fit all. We need to look at the policies that are driven for people because will discriminate and that can be seen in the workplace as well sometimes with our policies and our procedures and then we also need to treat the individual like we treat them when we are caring for them. And the Carl Roger's impact has aided mental health, also created people as individuals and created people that are creative, it also has produced some of the leading visionaries in the world and some of the top business leaders and the Carl Rogers in practise should be for everyday people, everybody in the room is important

and we got support workers, all need that support as well. And just broken down this as an acronym, Carl, create meaning, add support, relate, understanding, listen to and meet the needs of all and combine the four to focus on all the parties. Then I just put in there humans are not numbers so we are not just a number, we are individual, we're not machines and if we take that step back and look at the person as an individual we can actually unleash the potential and industry usually impact the mental health through support and learning, that can all make a difference. It doesn't matter how small or how large, we are all important. And that's it, if anybody has got any questions?

>> Thank you Jeannette.

>> Jeannette: No problem.

>>Adrian: Probably worth mentioning this is the first time --

>> Yeah the first time I've done anything like this big. A bit more, but still -- yeah, thank you.

>>Adrian: Thank you very much. Our second speaker this afternoon is Paul Boyle who comes from Brighton University on the south coast of England. He is going to be talking to us this afternoon about dealing with young people with cerebral palsy.

>> Paul: Okay. Okay. Right well good afternoon everybody, can you hear me okay? This is really quite strange, talking into it but I can't hear my voice out there so I'm hoping that you can hear me. My name is Paul Boyle, senior lecturer at University of Brighton, Occupational Therapist background. Really pleased to be here, good Congress, don't you think? Today and yesterday, really interesting discussions, some excellent speakers. What has come out to me is words like dignity, respect, social inclusion, social exclusion and I know this anyways, but nothing about us without us. And that really resonates with me with patient public consultation to form research studies. I'm here today to talk to you about a research study that I want to carry out about the lived experience, join transition, growing up that is from adolescence to adulthood for young people with Cerebral Palsy. And I really want to hear what your views are. So please do respond to my e-mail, which will be at the end of the presentation, or come and see me later today or here tomorrow. E-mail me and phone me up, have a chat, have a cup of tea with me, I would be really interested to hear what you think about the aim of this study. I want to consult widely. So what I will cover today is a background sort of study, why I'm interested in this phenomenon. Talk a little bit about what I'm trying to find out. I might, depending on how much time we have, spend a little time on the research design. Some of you may be interested in qualitative inquiry, some of you may not be. Some of you may be interested in philosophy, some of you might not be. Relatively new to me, come from quite a scientific background. But before I go further I just want to say a very short story about someone I worked with several years ago. Very disabled, permanent wheelchair user, 17 year old young man in a big loving family, very bright, very intelligent, when

went to University like all much his brothers, from Edinburgh, one from Bristol, where do you think he studied? The Open University, you heard of Open University some UK people will, fantastic organization. They can reach out to provide Higher Education into people's homes, fantastic. This young man missed out on the whole student experience, that really resonates with me. Universities have got much better but I think there is a lot more we can do. So the broad background, for many years for people with severe levels of disability, very well aware of high demands, but there is a lot of people in the UK mildly disabled, very disabled, a lot of people with Cerebral Palsy and I think all of us have high expectations about what we expect. We value social inclusion, talk a lot more now about quality of life we can expect levels of disability, but much more curious about qualitative life. If we think about what growing up is actually, just one study here I was drawn to, it explains that growing up involves completing education, starting employment and answering long-term close relationships and becoming increasingly independent. But disabled young people it's pretty clear to me, have a difficult transition, a difficult period between 15 to 25 and that transition into adulthood. Two-thirds of family with a disabled child don't feel accepted within their community. Disabled people are twice as likely to live below the poverty line as non-disabled people. It's not all together encouraging. I looked at the literature and there is many, many studies actually, not a great deal in the United Kingdom, so for example [Name?] others in Australia found young people are much more likely to be single, unemployed, live with their parents, have limited finance. In Canada they found that young people during ages of 18 to 25 can experience fear, sadness and abandonment as they transition from children services to adult services. This disturbed me. Found in Sweden, a lot of good studies coming out of Sweden, about the age of 17 to 18 young people weren't ready for that transition from children to adult services. A gradual transition is necessary, more support is required, so young people feel a sense of participation in society. That appeals to me, concept of participation, participating in society. In the United States last year carried out descriptive phenology with young people between 19 and 25, she found these young people as prepared to move into adult services have expertise about conditions and their needs but they struggle to negotiate new systems and therefore accept less than was expected. That really resonated with me having expertise but accepting less. So what I'm trying to find out is we know that services for children in the United Kingdom are quite well established actually for youngsters with Cerebral Palsy. When they move through services there appears to be some difficulties, some problems. Most concern for me, however, is problematic from adolescence to adulthood when all young people also have trouble and exciting times they go through. But young people with Cerebral Palsy can experience fear, sadness, abandonment, yet have expertise about their condition. That's what I found particularly disturbing and raises questions in my mind. Questions around what you had when you were 17 or 18 or 19, ambition, aspiration, social inclusion, maybe you had high expectations, maybe some of you had low expectations, or within your family. Interested, what does that

really mean here and now? And also in the future. I'm going to talk about methodology if I have time, quite interested in that whole world we live in out there in culture how it impacts on how we perceive ourselves and the world we live in. In particular this sort of thorny consult of growing up, we might all think back on our growing up years if you like and that becoming an adult. No longer a child, but becoming an adult. I hope to publish findings that had meaning for young people with Cerebral Palsy and especially for those that work with Cerebral Palsy, I think practitioners, best intentions in the world, think they know a lot, do know a lot, but really maybe need to know more about daily reality of living with Cerebral Palsy in Britain today. My researching, this is what I'm really interested to hear what you think and you can e-mail me, come up with me and have a chat with me and I would love to hear from young people who got Cerebral Palsy and their families and parents and siblings. I'm hoping the study will help us understand what life is like, really like for young people with Cerebral Palsy, join the transition from adolescence to adulthood. So to find out how to promote positive life opportunities. Not just provide care or management, not just to provide some access to school and colleges, but to provide real meaningful positive life opportunities. So my research question at the moment is what is the experience of transitioning from adolescence to adulthood for young people with Cerebral Palsy. There are some studies out there that contribute towards this body of thought, particularly from Scandinavia, Sweden, not in the UK and not from the methodology that I'm interested in. So please have a think and let me know your thoughts. So for me the research design increasingly phenomenon of living or maturing or growing up with disability has become much more relevant and it is this becoming an adult that I want to focus on, find out more about it. Including some of us that come from a hard science background maybe. How people make sense of the world around them is difficult to measure and quantify and I'm quite comfortable with measurement and quantification. How do we find out how people really make sense of that world around them. One thing that's difficult to measure, much more interested in subject of experience of maybe mobility, education, friendship, housing, poor housing, stigma, discrimination, five minutes, goodness me. So much more drawn to the philosophical concepts now of phenomenology, this may or may not appeal to you but there are many philosophers, that are contributors to philosophical thoughts, what we call descriptive phenomenology, argued our experiences can be measured scientifically, a positivist, he argued that we could study experience as it appears to us in consciousness. He argued that we would have to suspend our attitudes and beliefs, so I would have to put to one side all of my experience to access my participants consciousness of lived experience. And he argued there was a phenomenological reduction, we have a natural attitude about the world we live in. We have to become sophisticated to enter into this phenomenological attitude to access experiences, their lived experience. Well I struggle with that, because I have a lot of experience, I have Occupational Therapist, the much more drawn towards phenomenology, sounds complex but relatively straight forward actually, we argue we don't live in this isolated world, we live in a world with

everybody else, being in the world, concept, to really get understanding of their lived experience in their world. I need to get this to throw lights out on that. That makes sense to me. Because my approach, if I follow this line of thought, I would make sense of my interpretations of young people I'm talking to and their interpretations of the world they live in. The culture, civilization, the objects around them, language, discrimination, support, excitement that they might feel, all of those social variables, this is a much more worldly perspective that helps the researcher throw lights on that lived experience, true lived experience and it is the interpretation of people's meaning making that I'm drawn towards at the moment. Now these are big philosophical concept that is are simply help me find out more about lived experience, what life is like for these young people as they become adults. So I just wanted to remind you of why I came here today just to share with you my aim and research question, which is here. I will be really interested to hear, either question and answer session or e-mail me, telephone me, come up to me, I'll be here today and tomorrow and if people are interested, I think, that brings me to the end of my presentation. Thanks for listening. [APPLAUSE]

>>Adrian: If you have questions it becomes, if you could hold them to the end that would be great. Thank you very much. [speaker off mic]

>> [speaker off mic]

>>Adrian: Okay, yeah, thank you. I was going to make reference to that because it occurred to me when Paul was talking that I'm not, I'm not a natural liberal should I say, but I have had experiences in my life, which have made me question my attitude about equality. One of them relates to a colleague who had Cerebral Palsy. Like, you probably never meet him, long way away from me. I started working with this guy, I would say probably [speaker off mic] a few years ago and I first thought looked a bit mess I didn't realize. I didn't realize his background and I got to know him a little bit. And I thought at first, can't do this very well, why doesn't he get somebody to do it? Then it dawned on me, why should he, he was happy, was a great worker, was a great colleague, why does he need anybody to tell him how to run his life, not change attitudes, anyway, going to move on to our third speaker Silke who is here from Germany who is going to talk to us about occupational therapy, sorry, for people. Yes, thank you.

>> Silke: Yes, thank you very much, good afternoon everyone. My name is Silke Tophoven working at Institute for Employment Research, Research institute of federal employment agency in Germany. What I'm going to present today is a joint work of my colleagues, also here today and me the topic of the presentation is specifics of young adults with psychological disabilities in occupational rehabilitation. I first have to say some words about the situation in Germany and what we see is um, in Germany occupational rehabilitation helps people with disabilities to return to work, but occupational rehabilitation also the first labour market integration for young people with disabilities or house problems, in the process from transition from school to work occupational rehabilitation is also a measure to, to make young people

enter the labour market. And you see on the slide we have a process, the way young people go from school often is from special school in Germany still to occupational rehabilitation to obtain vocational training and then the aim of this process is the labour market integration of young people. Oh I think there is one thing, about those young people we should keep in mind that the group of these young adults is characterized by often learning disabilities versus, versus a share of about 50% and in recent years we observe growing number of people with psychological disabilities which is about 20% in 2014 and as we already heard before, the transition from youth to adulthood was several challenges for everyone and for one of our groups the challenges are even bigger. For example, for with disabilities, this study we focus on the transition from adulthood, from adulthood to neighbor market to young adults with psychological disabilities. The aim of the study is to describe specifics of young adults with disabilities in occupational rehabilitation and the obstacles they have to overcome during their transition from school to work. And first of all psychological disabilities, diseases are a complex, psychological disorder is a very broad category and which covers wide range of diseases such as schizophrenia, Nordic disorders, depression or addiction, plus we have a very wide range of diagnosis and disabilities within these category, within this category. And with regard to first labour market integration, especially the persistent crosses of more psychological diseases challenge affected persons as well as all other involved parties. For example, teachers at school but also the parents, the occupational rehabilitation managers and all the parties are challenged by these diseases or disabilities. We are doing so, this study what, we are doing is we are using a mixed method approach, plus we are using administrative data of German federal employment agency and we have representative information on all people starting occupational rehabilitation between 2007 and 2014 and we focus on those young people who are in occupational rehabilitation in order to obtain first labour market integration and we have a special, closer look into the group of people with psychological disabilities. What we also use is that we have 16 in-depth interviews with young adults in occupational rehabilitation, which allows for a description of specific life, context and occupational rehabilitation process and from this perspective, which is really missing in the administrative data. First of all we have some results from the administrative data and what we have here is that we can, that we have a group of those with psychological disabilities in comparison to the total population of young adults and what we see is we have a similar, males and females in both groups but one interesting finding is already in the descriptions that those people with psychological disabilities are older and those in the total population are younger. We have a higher share of both 21 years old and older, in the population of those with psychological disabilities and we have a high share of those under the age of 17 or 17 to, to years old in the total population. With regards to educational level we see that in the group of those with psychological disabilities we have a Higher Educational level in comparison to the total population. What we should keep in mind those with psychological disabilities in occupational rehabilitation process, in order

to obtain first labour markets integration are older and they have a Higher Education level. We see the status before this is very different between general population and those with psychological disabilities we see if we have a look with this, rehabilitation process and among those with psychological disabilities we have a higher share who have other status before they enter the rehabilitation process. -789D the we have a share around 50% who immediately come from school and we only have a share of 20% who came directly from school into the rehabilitation process among those with psychological disabilities of the so now I take a closer look into the transition into occupational rehabilitation also from qualitative material and what we find here is that the in-depth interviews reflect the beginning of the disease, possible causes and cause of the diseases and we took a look, take a look at these situation in order to get information on the different process into occupational rehabilitation after school among this group. We find that with the beginning of psychological disease they often, perceived overload as well as unsuccessful attempts to find vocational training, employment, critical family situation, simply problems during property we find they experience long periods of this, recovery after school or already doing schooling which makes the situation, the transition from school to work um different for them. Here I brought two quotes to illustrate what I mean. We have a young man, 24 years old and he says I try to find a vocational training position and it did not work, at the end of schooling I had such things, then I developed social phobia. Actually I did nothing at all for about four years in terms of vocational training. As I was in therapy and then we have a quote of young woman, 24 years old, said I quit school during 12th grade I was too long, I attempted suicide came into psychiatric hospital, afterwards came into a girls living community, therapy for two years. So what we get from this quote is that they have long periods from school to work because they also have to recover and have to, this time not able to do anything else than focusing on their disability or their disease and try to recover. Also interesting that having these results we are able to understand our administrative data in a better way. Now I decided to focus on one element of the rehabilitation process which is vocational training as a key element of occupational rehabilitation again we have some numbers from administrative data, almost 40% of young people with psychological disabilities visit vocational training programs, during occupational rehabilitation and we also see that most young rehabilitation participate in vocational training measures within vocational training centres, especially those with psychological disabilities. 76% participate with within vocational training centers and less young rehabilitation obtain regular company in terms of vocational training with or without subsidies and among those with psychological disabilities only 24%. To understand that we have to also keep in mind in Germany most of young people do their regular, do their vocational training within a company. So there is a big difference to the general population of young adults and also difference between the general population within rehabilitation process, vocational rehabilitation process of those with psychological disabilities. Here we get another quote from qualitative material and there is a young man, 25 years old and he is saying that completing normal company

vocational training would possibly not be successful. I would fail again. I'm not completely fit. I would like to complete this vocational training within the vocational training centre. So this young man has already had different attempts to find a way to labour market integration, here he is describing the process he doesn't want to fail again. He tries to make sure that he will manage to do one vocational training in order to have perspective and also it is very important for him to, to do very normal thing and also to get a certificate of the vocational training. Now I come to the summary of my findings and what we can say until today, we have in comparison to the population of occupational rehabilitation in general, perpendiculars with psychological disabilities are older and have a Higher Educational level which comes from the administrative data more often showed, therapy, pathways into occupational rehabilitation. This is an important point as we have for most children with disabilities, adults with disabilities we have a very structured pass into programs, but for both in mental disabilities which mental diseases, some point in their life. There is a different pathway into something to integration into the labour market. The biographical, biographical in-depth interviews show that the stabilization of the psychological diseases are essential before the process of occupational rehabilitation and the vocational training measures and occupational orientation. But we also find that the stabilization process is not at the end when the vocational rehabilitation starts, it also has to be ensured that the stabilization is also given during the process of occupational rehabilitation. For young adults completing vocational training is the key element within the process of occupational rehabilitation to have a labour market perspective. Few confusions, psychological disabilities is a challenge for the school system as well as the vocational training system in Germany and the occupational rehabilitation system and an ongoing support as well as good transition management seems to be central for group of young adults with psychological disabilities. In addition, another challenge is to design the occupational rehabilitation process as well as the school system in Germany in a more inclusive manner as we have very specialized institutions at the moment. So thank you very much for your attention and I'm very happy to get some questions or also some other insights from other countries, thank you. [APPLAUSE]

>>Adrian: Right on cue. Right. Our final speaker session is Julie, who is going to speak to us a little bit about mental health issues in prison.

>>Julie: Okay. All right. Okay. All right. Thanks the -- yes, please. What do we do when we have to change slides?

>>Adrian: Your responses right there.

>>Julie: All right. Just press that little bit there. Oh that one on the right, okay, lovely, thank you. Okay. Okay, thank you. Okay, thank you, lovely. Thank you. All right. Hello again ladies and gentlemen, thank you for all of your help. I'm here today to speak to you about people, fellow human beings who have disability and are either in prison or visiting prison. My perspective is that of a survival of

multiple crimes starting in childhood ranging from stolen belongings through every kind to even torture. It is also that of a woman with multiple disabilities who has visited prison and seen first-hand many of the difficulties I'll be presenting today. I'll speak to the issue, to the UK prison service in particular, citing examples from current prisoners with disabilities and my personal experience as a visitor. Will speak to the deeper causality of crime, the influence of the general public and suggest potential ways forward. My name is Julie Pitts and it is my hope I will do such a huge issue, some level of justice, if you pardon the pun, in the 15 minutes available, and be able to give a voice to those who have none. Everyone in this room, in this country, across the world are all human. We all have the same basic rights, defined in the Universal declaration of human rights, European convention on human rights and more recently the UN convention on the rights of people with disability. We all make mistakes. All countries have laws and people who intentionally or unintentionally break the laws, including people with disability. But most, most of the prison systems that are in affect are ineffective, stop reoffending and generally overwhelmed. I believe this is primarily due to a lack of clarity at the highest levels of the purpose of a prison and consequently the role of a prison officer within that system. UK prison service currently the purpose of prison to be as the slide says, her Magistry prison service serves the public by keeping in custody those committed by the courts. Our duty so to look after that with humanity and help them useful lives in custody and after release. Unfortunately the UK prison services not fulfilling this duty from the people that I've spoken with in prison. It is a problem that is consistent across the world, not just the UK government. They are struggling to decide what a prison is for. Is it for security to keep those people outside safe from harm? Is it to reform people? For punishment, to prevent and stop challenging behaviours. Or is it to rehabilitate people that made terrible errors in judgement so they can be reintegrated into society. Forgive me -- when you think of rehabilitation and integration with disability you are usually thinking of somebody who is trying to be rehabilitated and think need to adjust the new situation or something like that. And then they need to integrate themselves back into the world of life as they had before. With prisoners who have disabilities you have a double whammy. And they serve double time as a result. The reason for that is because they have to be rehabilitated not just because of their disability but also because of whatever cause put them there in the first place. And then of course we have to try and rehabilitate and integrate into the actual society itself. The difference between these concepts has a direct long-term impact on prisoners, prison staff and the general public. Although the government decide the emphasis placed on these needs, that is often decided by the influence of the general public, of people like you. The people the government has to represent. Therefore a collective group and as individuals we can make a difference to those people with disabilities in prison by lending our voices for human rights irrespective of crime. It means setting aside your own judgmental attitudes that you may have and working from love and compassion rather than fear and hatred. Ultimately we are human beings, not human dogs. So we need

to be not focus on what they have done. The proposed alteration to deal with the dichotomy of these needs was done by Lord Ramsbafin [Name?] what it does do is by changing the wording you can change the emphasis of the government place on what they do. Instead of being all about security and keeping people hidden away, it then becomes more about helping them be human beings and being got when they come out. So he proposed it is our duty to help those committed by the Court to live useful and law abiding lives in prison and on release. With the qualification must not be allowed to escape and must be treated with humanity. Not allowed out but treat them with respect. To I will separate the dichotomy one prisoner came up against I have this little illustration here, for those who are visually impaired we have a Governor who sat at the table and a prison guard on the other side and they are having a conversation about the fact that there is a gentlemen, if you can see him through the window, climbing over the bars of the prison. Using a rope, in a wheelchair, of course, wearing a very nice hat. And they the Governor is asking, so tell me how did an 81 year old man in a wheelchair manage to escape. And he is saying well Governor, we let him have a hat to keep him warm and he used it as a disguise and we just could not see him. This is actually happened, not the escape I might add, but the reason for refusing a thermal hat, in prison, done very terrible things, but can't have a hat to keep him warm preventing a stroke when he goes outside, he doesn't have a coat because he didn't get it on the 28 days in entry to prison, going out now in the cold and rain hatless, I thought that might at least be a more fun way of illustrating it to you. Now then, to be fair, staff has problems themselves, how can they possibly know what their job is. They are going to keep shifting and changing according to whatever government might be around. To add to that you have inconsistency from one prison to another. When you are a visitor you don't get a little handbook saying here you go, this is how you go in, this is what you need to do, what you need to bring and what you definitely don't want to bring. They don't do that, 13 different phone calls and try to figure out and it varies from prison to prison. You think got it sorted in one place, they get moved, you move, you have to start all over again. You have the main problem of security versus humanity, that is the key. Everybody is so intent on throwing the key away and locking them up that they don't actually see anything else. The sort of things I have known have happened in these prisons and happening today in the UK, would be considered hancus acts by people outside. They would actually be put in prison for what they are doing. Prison has a difficult job because, society, not just shoving a load of people in a box and leaving them there. They have to do with education, health, religion, spiritual practices and other things, it is completely overwhelming. They have less resources and 50% more people going in. They have an ageing population and a lot of things to deal with. But that does not excuse the reasons for why they are behaving as they are. The one major problem I found doing this, trying to put this together, other than the fact it was completely overwhelming as a big issue, was the fact with disability every other thing whether you are in a minority group, if you are female, if you are over a certain age, there are specific statistics

relating to exactly how many people are where and when and why. Not for disability, you might manage it for a little bit of the mental health side of it, might be a few little tidbits there, but they guess, they use phrase estimate of course, they guess as to how many people are in that and do that by going all right, okay, well there are going to be this many people over the age of 60. They are going to have disability needs so I know what we will do, we will figure out how many that will be and get resources that way. They don't actually check or ask when they go in, so nice statistics, recent laws that have come in, requirements for disability, everything else but disability as a world isn't used. The other thing is the prison relationships. When you get a good prison officer who knows the job, he is actually interested in the people it can make a huge difference and change of this behaviour and can be much, much better. If you get a prison officer just doing that job, like the one he said to the gentlemen who needed a wheelchair himself to the toilet, now I don't have training for that, not from here to there, tough. So he had to mess himself shall we say because he couldn't get that was something going it is not my job. On the plus side some major things have been achieved despite the fact information and solutions have been around for 30 years. That's what I found shocking, this wasn't new. It is not new in the UK or new anywhere else. The queen, in her speech, was um helping by the biggest shake of a prison system part of the queen speech since Victorian times. To be fair it is much better than it was, it still isn't accessing information about disability, not addressing that specific element and I doubt very much when they are doing these nice new creations of buildings they are actually thinking of how they can make them accessible for old people, not just those who are able bodied, prison and court reform bill is about opening the prisons, with emphasis on training, rehabilitation and education. Which is wonderful, the only problem is like a couple gentlemen I have spoken with, they are placed on the lower level where it is all one level, but the education and the library and the food court is all on the upper level and there is no lift. So what are they supposed to do? They can't be rehabilitated because they can't access their educational programs, they can't have money to get outside because they can't get the jobs they are meant to do, so they are stuck. They have to rely on the kindness of other prisoners which are in prison for being unkind. Governors of new prisons have ability to contracts and establish more boards, more statistics, which is lovely to hear, but again nothing on disability. Causes tribunal, to reduce delays, which I think is lovely, but unfortunately it doesn't go far enough. That's the point, doing well to help other people, but the disabled, by disabled I mean learning, mental health, physical disability, anything and everything is under that category. They don't differentiate as a general rule. This is from the actual safeguarding prison rules and to me once you integrate one person, you integrate all. If you think it is okay to treat somebody like rubbish you have no right to expect anything for yourself, that simple. Abuse is actual failure to, civil liberties, bodily integrity, general or well-being whether intended or inadvertent including sexual relationships or financial transactions to which a person cannot or valid, human rights don't stop at the door, but you would never

know that. To give an example of the financial transactions one gentleman who is unable to access own food pays the other members of the prison to go and get his tray for him in the currency that's going at the time, package of biscuits, but when you don't have any money, income really in prison because you aren't able to go to work because it is on the wrong level, you don't have much money to spare for things like that. That is basically abuse of the abuse occurs when a person is isolated from support system, vulnerable in some way. And have no voice. It contrasts to the perception of punishment, influence the general public view and desire for revenge and the other one they have is about neglect. Neglect is failure to identify and meet the needs of prisoner. They are supposed to have social services worker in there that does the assessment but the new law states that unfortunately if the prison doesn't do its job, if the prisoner has to investigate it, not social services. Whether I spoke to social workers about this they told me that's not the reality at this point in time. Even over the actual rules there is a conflict. People don't really know what they are meant to be doing. For example, by knowing medical or physical care needs, failure to provide access to appropriate health care or support, with holding of the necessities of life such as medication, which is what has been happening. You've actually got one doctor in the prison who point blank refuses to come downstairs to see a prisoner, which I feel is outright discrimination, but most definitely neglect. Another gentleman who reported serious headache, been very ill, had a really bad headache. He knew it was really bad the prison guard went all right then went to the nurse, nurse didn't come she said I don't come down for headaches, six hours later rushed to the hospital near death, his blood pressure was so high he almost died. One of many examples. In the prison context neglect, relevant behaviour, they do have a duty of care, many of them to be fair do a wonderful job within the role they have. But again if their role is not clear how can they know what they are meant to be doing, how can they know how to treat people? Rehabilitation also acknowledges the importance and needs of family. Now you can actually get some people who specialized in this and they go in and visit the prisons, especially those who are most vulnerable. And you can have family, friends, staff lawyers, all these people have to access the prison. My visit went roughly like this. I went in, I had to go through all of being everything checked and things like this and wheeled in then I had to walk a long space which I didn't realize I would have to do. So I was worn out by this stage. And after that then go in, by I was told that I could not take my medication with me. I could have my epi pen so if I get stung by a bee or something, I'll survive it, and I could take my inhaler, but my pain medication, anti-inflammatories, various medications, a whole boxful, I couldn't take any of it, I was told what I would have to do is before I go in, have all my pain killers before I go through the door and try to manage how it happens. If any of you are used to chronic pain, generally speaking they don't work that way, they don't help that way.

So I came very close to collapse and six of them had to help me out of the prison and I managed them to convince them not to get an ambulance, that is just me. Other people who are far worse than me, who

can't even access the prison just on those grounds. The appropriate approach or attitude if you got prison guards dealing from security point of view, they are going to treat you as a threat, you are likely to bring something in seriously dodging, to whoever you go to see. Unfortunately the majority of people who are going to the prison aren't doing that and they need to have the appropriate respect and approach given to them. And not be treated like prisoners themselves, it is not a pleasant place to go. 40% of prisoners said support from their family and 36% said that seeing their children would help them stop reoffending in the future, tons of research out there that illustrates how that, how in a has impacted on people and helps in reoffending. Very important, if you always do what you've always done you always get what you always got. It is a lovely phrase, it runs off the tongue. Nations prisons, responsibility and blame only by taking responsibility as individuals and as a society can we change it and change especially constructive changes is what we are talking about is a personal choice so what can you do? Governments can listen to us, they can actually acted now, put into place the things they have as solutions 30 years ago. They can actually make those real, give them some obey the laws, once currently and make sure it follows through. Stop monitoring numbers accurately, actually do that for the disabled people not just everyone else, monitor to safeguard externally and be held accountable for their actions. Apparently a lot of the reason why things don't get processed is due to land on the Secretary of State door. I don't know how true that is, but that's the comment that I found. What can we do? Stop avoiding the issue, not the big elephant in the room, raise awareness, stop their fear of what they have done to rule their life. Take back your control. From love and compassion not hate, anger and fear. Take it in the US has set up a wonderful thing, philosophy impacts on all the prisons, the prison guards and anyone that goes in there and so supportive and it has made a huge difference in reoffending rates. Speak opening about this, don't be afraid to do it. Speak to the basic humanity involved not the conviction. Believe what you say. Lead by example, volunteer, research, think. Think, write, paint, create, tell the story and tell it loudly. A few last words for you to consider, those with sight issues, forgiveness liberates the soul, it removes fear which is why it is such a powerful tool. Somebody I greatly respect, Nelson Mandela said that. What you can do or dream you can, begin it, boldness has genius power and magic in it. Only engage and in the mind grows hearted, get it and the work will be completed. Wolfgang said that and it is valid today, in his time. For one human being to love another that is perhaps the most difficult of all tasks. The last test and proof, the work for which all other work is but preparation. They are still people, they still have needs and they need your help. Please don't be afraid to give it. Thank you. [APPLAUSE]

>>Adrian: Thank you to all our speakers. Now we do have some time for questions, so if you would like to ask a question if you would put your hand up and the microphone will come to you. If you could say who you are, where you are from and if the question is aimed at any one of our particular speakers that would be great. So any questions?

>>Audience Member: [speaker off mic]

>> Any questions, it can't be that good downstairs. Nope. Yes, question, that lady. Can you wait --

>>Audience Member: Oh sorry, yes, is this on. Can't hear it at all, that's really strange. And so I'm from a disability, my name is Alay [Name?] and it was in relation to mainly the first two speakers, yourself and, no sorry, yourself and the third speaker, yourself. It was, it was just a question I think it is really great to hear so many people coming from different kind of professional backgrounds and academic backgrounds who are really interested in the experiences of young people and how young people view themselves as well. That's the main kind of drive behind, disability lines we are user led, organization and we work with people of all ages from 14 up currently, 14 to 100. And we also run employability project basically non-statutory because we work with young people and people of, disabled people of all ages who often don't qualify for the employability support that is available through job centres and through statutory services often exactly what you, that when people leave school there is a complete wasteland I hate it when young disabled people are transitioning into adulthood, it can take years and years and years. I just wanted to ask generally through, whether there is anything in your findings about young people's experiences of external barriers, not just from their own impairments as well because particularly in relation to mental health, that's something that we have experienced as a younger, when I was younger as well. That is actually mainly attitudes and the lack of adaptations and the lack of support and understanding that make it difficult to get into employment or learning or progress through University or education. And it can take up, it can take people themselves a long time to realize it is not them that's at fault, it is the Society, then the way things are structured. So I think the point I want to make was that for any kind of research, especially working with young disabled people it would be great to I suppose have young, young disabled people's voices kind of being central to that and there is a lot that can be learned in drawing up like a research plan as well, right through the whole process, a few speakers here, the research and there is a few people I can get in touch with yourself, young people I know who are researchers with Cerebral Palsy who will probably be able to give you a lot of tips and information, context as well.

>>Adrian: Thank you --

>> I think that we also need to break down the barriers with regards to that as well and accept people for who they are, that will breakdown the differences.

>> Yeah interesting comments there, I agree with everything you are saying, and please do contact me, I would be, really, really keen to meet young people who have had some experience with everything you are talking about to help me form my study, it is a long-term study. I come from a hard scientific background much more interested in that lived experience, whatever that means, philosophically I need to put that in place, the design. What I would say is the literature I've looked at it is pretty compelling really in so far as not talking to each other between this, we know it is clunky, complicated, we know there is well-

intentioned people there but the services in the literature interface of systems and eligibility criteria, that sort of thing. So I'm hoping to throw some lights on the complications, young people are experiencing, let's hope it can improve results and better outcomes for those people.

>> Did you want to --

>> Yes I completely agree with you, what you said and you give the answer to some things already to yourself and I think one important thing was over in the first presentation about the hidden diseases and hidden disabilities people have to deal with that and also the employers and the labour market and you cannot see but someone has some difficulties or something he has to overcome, could be a more open society to overcome those problems, thank you for your comment.

>> My time in the government, the we commission some research, hasn't been published because it lacks a certain robustness but there is a lot of talk about this warehousing, where people leave school and are pushed into college courses and so on. The college courses we heard yesterday, might not be the most challenging for them, but they are the most comfortable if we can put it that way. And a lack of ambition both on sides of educator, occasionally people themselves, to what they might expect. We need to get over that. Okay another question for the lady.

>>Audience Member: My name is Francis, I'm a member from Disability Alliance my question is really to the gentlemen who is doing the research and also the lady from Germany, I know you are doing this research, which are wonderful, my question is the long-term for research, is it necessarily to, I know you are trying to make a difference but how can you include the government to ensure whatever you do find in your research, is that being put into use? It is one thing to do research and another to make sure it is making an impact in people's lives, not just to come in and have a talk, but we need to see something is being done. How are you intending to go about this, this is something put into action for the people of this condition, thank you.

>> Yes, thank you very much for your comment. As I did not mention my research, our research is founded by the federal Ministry of Social Affairs and the institute I'm working with in is actually doing research and also policy advice, so we try to make sure that our findings are also given to policy decision makers, but of course it is always a challenge for researchers to translate our findings into programs and into the government structure and the policy and bring those results to policymakers. Our research findings have to be translated to the policy, thank you.

>> Yeah just I agree, I think it is a, really involved in research to get our research out there and that doesn't just mean publication and academic journals, that's of course what we want to do but kind of conferences, it is going to more informal sessions, it is supporting disabled people organizations. We have seen many of them in the Southeast of England completely loss funding and gone under completely. I also think it is, upon our professional organizations to be accessing research material that's out there. Isn't it really

through civil society and organizations, trade Unions and pressure groups. But I can't, to any of our studies. The more evidence that is out there, policy should be based upon evidence so should be formed by evidence so I would feel reasonably comfortable putting some pressure on those decision makers.

>>Adrian: Thank you, any other questions? Last chance. Okay. Well thank you all very much for your participation and to our speakers, it has been a very interesting afternoon, thank you very much indeed. [APPLAUSE] Coffee is indeed being served downstairs.