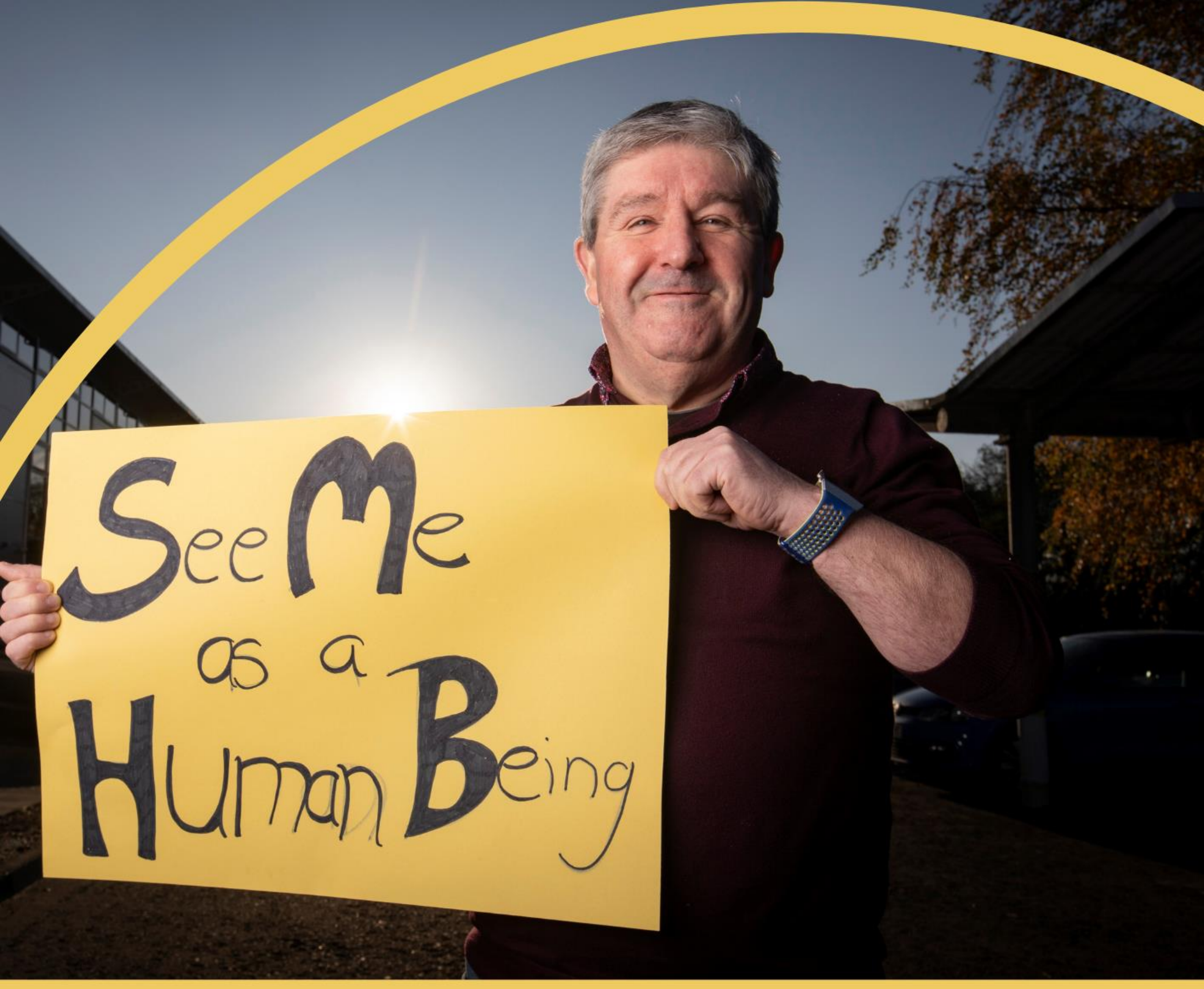

Appendices

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Disability Research on Independent Living & Learning
Disability Action
COMMUNITY FUND

Appendix 1
DRILL NAG and Research Partnership members

Members of the DRILL National Advisory Group (NAG) and the Research Partnership for the “See Me as a Human Being” Project

Please note that there are some cross-overs, with some people being on both research groups, so both groups are represented together.

Members of DRILL National Advisory Group members

1. Acheson, Nick Dr: Visiting Research Fellow, Trinity College Dublin

2. Davidson, Gavin: Senior Lecturer in Social Work, School of Sociology, Social Policy and Social Work, Queen’s University Belfast

3. Fall, David: Peer researcher

4. Harbinson, Dawn: Former Disability Tutor

5. Kelly, Berni, Dr: Senior Lecturer in Social Work, School of Sociology, Social Policy and Social Work, Queen’s University Belfast

6. Marshall, Ursula: Activist, Cookstown Disability Forum

7. Matthews, Heather: Activist, REAL Network

8. McAteer, Majella: Business Development Manager, British Deaf Association

9. McConkey, Roy, Prof.: Emeritus Professor of Developmental Disabilities, Ulster University

10. (Vice Chair) O’Reilly, Tony: Activist, North West Forum of People with Disabilities

11. Potter, Michael: Researcher Northern Ireland Assembly

12. (New) Sansome, Joanne: Activist with a disability

13. (Chairperson) Sheeran, Alan: Consultant (Disability and Children's issues)

14. Wilson, Monica: Disability Activist

"See Me as a Human Being" Research Partnership members

1. Acheson, Nick, Dr: Visiting Research Fellow, Trinity College Dublin (NI NAG member)

2. Bray, Patricia: Strategic Advisory Group, Disability Action and the North West Forum of People with Disabilities

3. Rooney, Paul: Northern Ireland Social Care Council

(replaced Maguire, Catherine: Professional Advisor, Northern Ireland Social Care Council)

4. Matthews, Heather: Activist, REAL Network (NI NAG member)

5. McParland, Sinead: Advocacy Team, Disability Action

6. Potter, Michael: Researcher Northern Ireland Assembly (NI NAG member)

7. Sansome, Joanne: Activist with a disability (NI NAG member)

8. Sheeran, Alan: Consultant, Disability and Children's issues (NI NAG member and chairperson)

9. Ursula Marshall: Cookstown Disability Forum, Disability Action NI Strategic Board

Appendix 2
Sample Interview Transcript

Transcribe It

Prepared For:	Disability Action
Recording Details:	V0119002
Date of Transcription:	16 August 2019
Recording Length:	22m

Int[1]: **Thanks so much, [name], for coming along, for being here, and being up for doing the research, I really appreciate it.**

The first thing I wanted to ask is, how would you describe your disability, or disabilities, just so I can use the right words?

R[2]: The walking.

Int: The walking, okay.

R: Yeah, but I'm really walking alright, but I've had a few accidents.

Int: You've had a few accidents, have you fallen?

R: Yeah.

Int: What do you use to walk?

R: I just use my feet, I don't need any sticks or nothing, I don't need it.

Int: That's really good to know.

We did some focus groups earlier, so some of the themes that have come out of this form part of the questions.

How did you find out about information to access social care? Tough question, how did you end up coming here?

R: When I ended up going here, [inaudible 0:01:19] years altogether, beginning of [inaudible 0:01:23] 1995, in July, 24 years, and I still like it.

Int: Did you come here to live?

R: I stayed here, I was in [inaudible 0:01:40], and I stayed here until it was finished, it was good, I enjoyed it, [inaudible 0:01:48].

Int: What kind of support do you get when you're here, what help do they give you?

R: Plenty of help.

Int: Can you give me some examples of what it's like to live in a residential home like this?

R: Showers and that, [inaudible 0:02:11] here, I shower every day, every evening, some of the staff help me out.

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[1] Interviewer

[2] Respondent

Int: **Do they cook all the food?**

R: Yeah, they do food.

Int: **Do you have activities with other people?**

R: Yeah, activities.

Int: **Do they support you in any other way, to be able to live independently?**

R: Independently?

Int: **Yeah, to do things, living independently doesn’t mean you have to do everything, but it means you get to choose.**

R: I get to choose what I want.

Int: **Could you give me some examples of that?**

R: Here?

Int: **Yeah, some examples of how you've been able to choose.**

R: Hmmm, let me think.

Int: **That’s alright, you just take your time, there's no rush at all.**

Are you able to walk any distance?

R: Yeah.

Int: **Do the staff help you to walk at all?**

R: No, I walk myself, I walk around the house every day.

Int: **You walk around the house every day?**

R: Yeah, ten laps.

Int: **Ten laps?**

R: Yeah.

Int: **Fantastic, it’s a good way of keeping yourself mobile.**

R: I know.

Int: **So they support your choice to do that, they don’t say, “You shouldn’t go walking”, they accept your choice to be able to do that?**

R: Yeah they do.

Int: **Do you feel like they listen to you, if you say, “I want to do this instead of that”?**

R: Yeah, they do listen to me, they're very good.

Int: How did you first find out about this place, do you remember?

R: How did I find out, I found out before I come up here, I was talking to [name], the manager, before I come up here, I see her, and then I went down, when was it, [inaudible 0:04:23], for a while, [inaudible 0:04:27] Centre, and then I left there to come up here. [Inaudible 0:04:30] before that, then here now.

Int: Did you live at home by yourself before?

R: Yeah.

Int: How did you find out about this place? Was there someone in your family that helped you, or did someone give you some information?

R: No, my family knew about it.

Int: Your family knew about it?

R: Yeah.

Int: So they told you about this place?

R: [Name] brought me up here, yeah, [name] brought me up here.

Int: Do you think you'll stay here?

R: Yeah, as long as I could, every day, five days a week I get to come up here.

Int: Do you sleep here, or do you go back home?

R: No, I sleep at home.

Int: So you come up here through the day?

R: Through the day.

Int: What are the other people like, that stay here as well?

R: Here?

Int: Yeah.

R: They're good.

Int: Yeah?

R: Yeah.

Int: You get on with people?

R: I do, yeah, no bother.

Int: That’s good.

Who would you say are the most important people that support you to make decisions?

R: Most important ones?

Int: Yeah, who are the most important people that help you to make decisions if you've got to make life decisions?

R: They help me to make decisions.

Int: Do they?

R: Yeah.

Int: Can you give me an example of how they help?

R: My sisters, when I was younger we had, my mum, my parents had ten in the family, two boys and eight girls, and when they got older and older, they helped me to make decisions.

Int: So your family have helped you to make decisions?

R: Yeah.

Int: What kind of life decisions do you think, independent living decisions, do you think they’ve helped you make?

R: I can't think of any.

Int: That’s okay.

R: When I get older, I can't stay on my own, I’ll go to a nursing place, I can't stay on my own, so when I get older and [inaudible 0:06:58].

Int: Do you think you'll live somewhere like here in the future, permanently?

R: Permanent?

Int: Yeah.

R: Yeah, [inaudible 0:07:08], that’s a place I like.

Int: Okay, so there's a nursing home that you like?

R: [Inaudible 0:07:18] live there, [inaudible 0:07:19].

Int: Do you live close by?

R: I only live here, my house is down there, in a wee park, just a five minute walk from here.

Int: Do you walk, or do you drive?

R: No I don’t drive at all, I walk.

Int: How do you get here?

R: Walk.

Int: You walk?

R: Yeah.

Int: Fantastic, it's good stuff.

R: Is it?

Int: Yeah.

R: [Inaudible 0:07:45] taxi, but then I need a taxi to go to [inaudible 0:07:54], or to go to the dentist, I need a taxi for that.

Int: I guess hospital visits and doctors.

R: I don't like going to any hospitals, horrible.

Int: Is there one nearby, if you need to go?

R: I had to go to A&E with my hand, the time I fell.

Int: When was that?

R: That was about [inaudible 0:08:23] now.

Int: Did you get good support for that?

R: My sister took me, and I had to get my hand x-rayed, it wasn't broken.

Int: That's good.

R: [Inaudible 0:08:38].

Int: Thank you for that.

The next theme that came out of the focus groups was about stereotyping, people might look at somebody who's disabled and make assumptions, or have ideas about what they can or can't do, just by looking a them.

Do you think that people have ever made assumptions about you?

R: Assumptions?

Int: Yeah.

R: What does assumptions …?

Int: Assumptions is like, I've got a stick that I use sometimes, if I'm using my stick people might make assumptions about how far I could walk, or that I'm not able to do certain things, or that I might need help with something.

So assumptions are not always a bad thing, but they might look at someone who’s disabled and not know how well they could think, how well they could understand things, and sometimes assumptions can be bad because they're being negative in their ideas about people.

Because the whole research is about attitudes, do you feel, with how people have treated you, that their attitudes towards you have impacted either in a positive or a negative way? If they think you're not capable of something, does that impact on you?

R: I don't know.

Int: Tough questions, aren't they?

R: I know, they are tough, sometimes it’s hard to explain.

Int: Do you feel that you're supported and respected by the people who provide your social care?

R: My social care?

Int: Yeah, so it would be like here.

R: Yeah, here?

Int: Do you feel they respect you?

R: They do, and I respect them too.

Int: And you respect them too?

R: Yeah.

Int: How do they treat you, give me an example of how they might respect you or support you in a day?

R: Helping me out and things.

Int: So if you need to go and talk to someone, is there always someone that you could talk to?

R: Yeah.

Int: If you need any medical care, would they help you?

R: Yeah.

Int: Do they have nurses come in?

R: Thank God I don’t have any nurses coming into my house, thank Lord, so far so good.

Int: If you could change anything about the way that people see you.

R: See me?

Int: **Yeah, if you could change anything about how people see you, what do you think you'd change?**

R: That I'd change?

Int: **Yeah.**

R: I don't know.

Int: **They're not straightforward questions, because it’s hard to know, you can only go, “Are they thinking about me in a particular way?”, and you don’t know for sure, but you get a vibe sometimes.**

Do you ever feel like people look at you and think negatively?

R: Negatively?

Int: **Yeah.**

R: I don't think so, they’ve very positive all of the time, I like to be positive all of the time.

Int: **You like to be positive?**

R: If I can.

Int: **Do you think other people are positive towards you, as someone with a disability, do you think people treat you well?**

R: I'd say they do.

Int: **When you're out and about, do they treat you well?**

R: Hmmm.

Int: **if you're at home, and you walk to the shops?**

R: Yeah.

Int: **People treat you well there?**

R: Yeah.

Int: **That’s good.**

The next one is about your experience as someone who is disabled, and being disabled isn’t all of you, it’s this bit of you, and then you've got all these other facets, but it is recognising, you've got this disability, and you know it, and you're doing your best to keep walking, yeah?

R: Yeah.

Int: **Do you feel that you have control over how you live your life?**

R: I have control?

Int: **Yeah.**

R: Yeah, I like to be in control.

Int: **So you feel like you've got control over how you get to live?**

R: Yeah.

Int: **You get to make decisions?**

R: Hmmm, I get to make decisions, and the right ones too.

Int: **Okay, like what?**

R: Everything.

Int: **Give me some examples, [name], because this is really useful for me to know, if you can think of any ways in which you've got control over your life, or ways that you've made decisions, big decisions.**

R: I can make decisions, if I can't [inaudible 0:13:44], I can make decisions myself, my sisters, they help me to make them.

Int: **So you have some support?**

R: I have support.

Int: **But no one will take over?**

R: Take over?

Int: **That decision.**

R: I don’t like people taking over me, no, I wouldn’t want that.

Int: **I don't think anyone would want that, but it does happen.**

R: It happens to some of them.

Int: **That’s what we want to understand, so it’s good that you're in a position that you feel like you can make these decisions.**

In terms of your daily routine, when you come here, do you have much control over what your day is like?

R: What my days are like?

Int: **Yeah.**

I'm sure there's some structure about when lunch is served, and things like that, but have you got control over what you want to do, say in the afternoon?

R: Yeah, I have control, like I can walk on my own.

Int: You can walk on your own?

R: Because there are people that need somebody to help them.

Int: Are there many people that need that kind of support?

R: Yeah.

Int: Is there anything that gets in the way of you having control?

R: Get in the way?

Int: Yeah, anything that makes it hard for you to feel like you're in control of your own life, anything that gets in the way.

R: No, I don't think so.

Int: Is there anything that helps you to have control?

R: Helps me?

Int: Yeah.

R: [No response]

Int: You talked about your sisters, is there anything else that would help you?

R: They help me.

Int: And they help you here?

R: Yeah.

Int: If you wanted to find out some information, say you needed information about something, would you know how to go about getting that information?

R: I think I could if I wanted.

Int: What would you do if you needed to find out some information?

R: Information?

Int: Yeah.

R: I don't know.

Int: Would you ask people here, would you feel able to do that?

R: I'd say I could.

Int: And your sisters?

R: My sisters.

Int: **When you come here, this is social care that they give you, can you tell me about a time when your social care was positive and helpful to you?**

R: Yeah, my social worker is [inaudible 0:16:40].

Int: **Okay, so you've got social workers?**

R: Yeah.

Int: **And what kind of support do they give you?**

R: [Inaudible 0:16:48] support.

Int: **Like what?**

R: They help me out with everything, everything, [inaudible 0:17:02], [name] got me in here.

Int: **They got you in here, the social workers?**

R: Yeah.

Int: **When was the last time that you saw them?**

R: Last time I saw them?

Int: **Yeah.**

R: It was quite a while ago.

Int: **Okay, so you haven’t seen them for a while?**

R: No.

Int: **Have you see them since you started coming here?**

R: Yeah, she comes back now and then.

Int: **Could you tell me about a time when your social care was negative and not helpful to you?**

R: I've never seen anything negative to me.

Int: **You've not had any social workers or social care workers …**

R: That were negative?

Int: **Yeah.**

R: Never for me anyway.

Int: **That’s good, this is about your lived experience.**

Do you get consistent care from carers?

R: I do get carers, I do every morning.

Int: What happens every morning?

R: She gives me, she gets my cornflakes ready, when she comes, and she makes me a cup of tea when she comes in, and then two ladies come and see me, help me out, Saturday, every other Saturday.

Int: What kind of support do they give you?

R: They make me, get my breakfast ready, cup of tea, and then they come back at the end of the day and bring me something warm in the wintertime, you know, and in the summertime you don't need anything too warm.

Int: So they help you, if you've got to do any cooking, if you've got anything that needs to be cooked or heated up, they'll come and do that, so they're social care workers that come to your house.

What's been their attitude towards you, do you feel like they're thinking positively of you, or negative?

R: I've never seen them negative of me, they're very good.

Int: They listen to you?

R: Yeah, they do.

Int: Can you ask them, if you didn't want this, could you ask for that?

R: Yeah.

Int: That's great.

Do you get consistent care, do you get the same care workers coming in?

R: Yeah, the same ones.

Int: The same ones?

R: Yeah.

Int: What difference does it make to you, that it's the same care workers?

R: The same?

Int: Yeah, does that make a difference to you?

R: I do like them coming in.

Int: If they were different people, would that be difficult?

R: I don't know, I had [inaudible 0:20:13], I had them one time for a while, and they left, and then new ones started, this is the first Trust that they're doing, the ones that come to me now, from the Trust.

Int: **What was the care like before?**

R: They were good too.

Int: **That’s really good.**

Could you tell me one thing about how the social care that you receive, either through the social care workers that come to your house, or the support you get here, how has it helped you to live the life that you want to live?

R: Hmmm.

Int: **Can you think of one example that you could give me?**

R: To live?

Int: **Yeah, how has the social care that you get helped you live the life that you want to live, or the way that you want to live it?**

R: They're very good.

Int: **They're very good?**

R: Yeah.

Int: **Excellent.**

R: That’s all I can give you.

Int: **That’s fine, this is about your experience, so I really appreciate it.**

Is there anything, if you think about, is there anything about your social care that you ideally, in an ideal world, would like changed?

R: I think I have enough, with them coming here to me.

Int: **So you get good social care?**

R: Yeah.

Int: **Good stuff.**

Thank you so much, [name], I really appreciate it.

[CLOSE]

Appendix 3
Focus Group Transcript, Social Workers

Transcribe It

Prepared For:	Disability Action
Recording Details:	V0617001 - Focus Group - Social Workers
Date of Transcription:	15 August 2019
Recording Length:	52m

[Introduction, background and housekeeping]

Int: **So, without further ado, I'm just going to get into the discussion questions since we don't have that much time. As I said, our main focus is how attitudes impact on independent living, and by attitudes we mean thoughts or feelings or knowledge that we may be aware of, or we may not be aware of, that ultimately impact on our care. So, my first question is what attitudes towards disabled people do you think exist in the adult social care system? And have you witnessed any either directly in your work, or have you noticed something in the practice, or have you heard a story that you think is relevant?**

R: I think that from a staff perspective some of the staff have a feeling of protecting service users, and that protection because they have a disability whatever it may be, whatever it's cognitive to dementia or a physical disability. There's a real emphasis on functioning and protection, and I think it's about striving to say if you actually spoke with the service user and what they want to achieve in life, it's about creating positive thinking, and I think we all could benefit from promoting positive risk taking. And enabling people to reach and fulfil their optimum. I think as regulated services, we've become so risk averse, sometimes we stifle the person in terms of the services that we provide.

R: I would agree [name], because quite often we'll find we're sometimes, you know, people do want to take a risk, a very positive risk and staff are willing to support that, they'll find that the regulators they'll try and block it when they come in to do inspections and visits. They'll be going, "Well how can we possibly do that, that couldn't be allowed?" You know, so I was at a meeting recently it was aimed around people with their own meds if they moved into residential nursing and supported living. Especially around controlled drugs, and a lot of the nurses in the room said, "How can you dare let anybody hold their own meds, especially controlled drugs in their room?" We were going, "Why not, they do it at home?" You know, so there's a culture within the medical side, and the nursing side also that sort of blocks people from that independence as well.

R: I suppose we have a bit of experience of that, I mean our business is mainly domiciliary care, so it's supporting the clients in their own home, so I suppose if somebody is a new client or an existing client that's gone into hospital or becomes unwell or develops a disability and it's something that's new, something we haven't come across before, it's something different [inaudible 0:10:58] fear because it's something that's unknown, so it's a learning for them. Depending what it is obviously we would be training on whatever would be required. But there could be a bit of disturbance if it's something different.

R: I think the other thing to remember as well is, where family are heavily involved, and there's an opinion by family that care and support should be a certain way, and the service user wants something different, I think it's about training and supporting our staff to look at the best interest pathway, and to start challenging sometimes the notion that if the service user wants to take part, whether they should be allowed. But that support specific training around best interest, how to make sure legally that decisions around [inaudible 0:11:49] challenged, that we have done everything in the correct way. And there should be some learning around that.

Int: **So this is a completely different training [inaudible 0:12:17] the positive risk-taking, both sides will benefit from a conversation on enhancing risk-taking as opposed to stifling it. So, that leads me to the next question, on attitudes towards disabled people. And by the way you can keep expanding on the definition of attitudes, and what attitudes you have witnessed. Would you say from your perspective are they an enhancement to independent living, or are they a barrier to independent living?**

R: I suppose it depends on my understanding [inaudible 0:13:03]. In a way it depends who you're with, and who you talk to, this can be both. You know, I've had people with a nurse live-in services, who has said, "Oh I couldn't possibly manage my own meds because that means I'll have to move out, and I'd lose of my benefits." Because that's the attitude that other people have talked to them about. You know, they have listened to all the stories from the past or, "Oh if you do that, they'll cut your money, if you do that you'll have to move out of your home." We're trying to enforce people, "No as long as you still need support and care, you can remain living here, and if your needs change, we can support you." But I suppose coming from families and coming from generations of, "Don't be doing that because they'll cut your benefits," you know, there is still very much that culture within certain areas.

R: I think unfortunately the Universal Credit system is going to just really enforce that with people as well. Because we're already seeing in the media stories about people having lost benefits who are extremely disabled and ill and need a lot of support. You know, those attitudes I think are going to get more ingrained rather than less ingrained actually.

R: I suppose for us too, because we are supporting people with mental health, which is not always obvious. People do still have an attitude, "So what's wrong with you?" And it's very hard for some people to get past that, unless you can see the disability, people's attitudes are, "Well sure there's nothing wrong with you."

R: I think your previous point was very well made, Universal Credit encourages society to... We don't get give people consent to focus on what they can do, we give them consent to focus on their disability, and that's a crime to the family because of Universal Credit. We encourage that, and we encourage that ethos, and that's bad you know.

Int: **What about attitudes more specifically in the context of adult social care? Can you think of an example of where attitudes will be a barrier, but also an example if you had it where attitudes could be an enhancement to independent living?**

R: I was going to give you an example going the other way, so apologies for chipping in, because I kind of said that I was – and [name] on the speakerphone over there. So, I'm here from Sure Start [sounds like] but my background is learning disabilities and challenging behaviour services, but primarily in Ireland and Scotland. And some of the questions were just making me think about services users around disabilities that we supported to access more independent living services.

So we supported them in the Community Team, and they had a Domiciliary Care Team in place, but it wasn't effective in meeting their needs. But there seemed to be an attitude that they didn't have a choice, it was, you know, we're there to provide a service and the service is at these times of day regardless of what your choices are. And consequently then we had to deal with a number of challenging behaviour issues, where when we did a full analysis of the environmental situation on what was being done to them, as opposed to what they wanted, and changed the set-up so it was more independent.

So it took into account what they wanted, when they wanted their care, and how we could supply that to them. Then that significantly changed everything for them to be honest when it came down to their quality of life improvement. So, I don't know if that kind of fits the criteria in terms of attitude? There was some very positive attitudes within that situation as well, around what they can do, what they should have access to, but primarily even listening.

So, instead of the service being provided at the time of their favourite TV programme, and then being surprised when we saw some challenging behaviours, we can move that service provision to a time that actually suits them. You know, even those tiny things make the world of difference. But some of the team that we were working with at that time, really struggled with the idea that interrupting somebody's TV programme could be a difficulty for them and would actually impact their quality of life. I think sometimes it's very easy to forget those tiny little things, that apparently seem small, and it's attributing those important aspects to our client group as much as to us as well.

R: And there was something similar with our care packages brought into us in the supported living in the past, and we had one in particular and we had actually asked them to stop the care package because somebody came in at 10 o'clock, and the person was getting up at 10:00. They would come back at 12:00, and they're back at 4:00 and they're back at 6:00 and that person was to go to bed at 6 o'clock. And this is someone who would have gone to bed at 10:30,11:00 and suddenly because they didn't fit into the run, "This is our run, we have to come to you at this time." We had to say sorry, but you know, just stop the whole package because the system [overtalking].

R: I don't think [inaudible 0:18:37] attitude, I think that's to do with demand on the service.

R: I was just going to say, I think that's a system issue sometimes.

R: We certainly had services where people provided care for, and what we've had to do is a big retraining and changing the culture to reablement, that you do with and you encourage. And I've found a great difficult in active society, have great difficulty with that. In adult social care it's about creating a model of support and empowerment. That's a different way of working to the way we always did things [inaudible 0:19:12]. Our team has had to change, but it's slow, and staff have to get permission to do things a certain way, because some of them fear if they don't do for, something will go wrong and they'll lose their registration, which causes them to be more risk averse. And that has a knock-on effect, and I think attitude is very important, but it's a contract change we need, to say we need to be doing with, not for our service users, to encourage them to reach their optimum.

R: Yeah, and there’s that difference between with and not for, and with and not to as well, which like you say is cultural. But attitude and culture are so closely aligned.

Int: Can I just explore further, this is extremely interesting to me, this cultural change to do social care with people instead of for people, where does that culture that needs changing come from? Where is that assumption that people on one side people are refusing to let go of the control and on the other side people are not keen to take the control? Where does that come from? Is there something inherent about disability and the adult social care that dictates that culture?

R: I think our models of care we have [inaudible 0:20:59] over bed based, institutional based, we have residential homes and nursing homes, and that’s what gave us the [inaudible 0:21:03] priority. Community care changed all that, and with people now living in their own homes and it’s their right that they – it always was even in residential the person’s right to do things the way they wanted. But [inaudible 0:21:19] it becomes institutional, and the way we did things was to provide more. Community care has really challenged us, and that’s everybody, every trust and every person in society that a 90 year old can be in her own home with care and support, that’s a big challenge for everybody in society, because years ago 90 year olds went into care. So, we all have to change our thinking, and community care has to be challenged everywhere.

R: I think some of that is driven by the system that you referred to, because I was recently just reading the Department of Health’s Workforce Plan document, and they were saying something like, I think it was something like they reckon they’re going to need 1400 more care workers per year for the life of the plan. And I can’t for the life of me see where that pool of people are going to come from, because there are already not enough places to have care packages at home for people who want to come home, out of hospital for example. And even the tension even between medical and social, and I’m talking from personal experience here, where my father was in hospital and the doctor was saying, “If you want him home you can take him home, it will be grand, talk to the social worker.”

And that was okay, so the social worker came, and she said, “Oh yes we'll talk about a care package.” And within a day, there was conflict between the two where, “We don’t know whether this is happening or whether it’s not.” The family actually went to ask, and we discovered that on the medical side, my father had pneumonia, but the social worker hadn’t been informed about it. So she was working a way trying to get a care package for a man who had he left hospital at that point would have most certainly died. You know, so there’s that information block in some of this as well, so I can’t see how you can work along with someone to do what they would like, if the professionals aren’t having the conversations that need to be had about that, that keep you both safe.

And actually when it came down to it, it was a very competent nurse who said, “I will not let you take your father home, because if you try and take him home without that care package in place, he’ll not even make it in the ambulance back home.” So, another professional stepped in, so there’s that sort of conflict between the bed blocking thing, “Get them out of hospital, they’re bed blocking, they want to go home anyway.”

Alongside a system that's struggling to get care packages. I mean with the greatest will in the world I've seen some of those people coming in, a lot of them are quite... The younger end of the age spectrum for the most part, and I sometimes don't think that they actually appreciate... This might just be an age thing for me, I certainly wonder, you know, it might be about they're given the training, but you can train somebody, but unless they've actually seen it and done it, it's a very different thing. And what you think you could deal with on paper, when you're actually faced with it, is something completely different. So I think there's something as well about how those care workers, where they can be had, are trained and developed and formed.

R: Can I just go in there and say something about some of the stuff that we're doing in NISCC and trying to overcome some of those attitudes? Myraid is doing a lot of this work on another side. At the moment we're in the middle or we're coming to the end of a pilot, we've a month of it left on the value based recruitment programme, looking that those attitudes of people. Looking at their values, so that when they do come in, they're coming from that good core value base, whether they're young or in their 40s, or even in their 60s and 70s, because they still have good experience and good knowledge there. But it's looking at the core values of the individuals.

And [name] I was talking to a few of your care managers at the focus group, at the Social Care Managers' Forum, and they explained how they had introduced, you had introduced value based recruitment, how they were reluctant to use it. But after the very first interview both [overtalking] thought this is brilliant, this is what we should be doing. And the confidence stuff was good, but that value stuff they said was invaluable to them, totally, totally invaluable. And we're also working in a lot of other areas just around developing resources for organisations to use with their staff. So, what you're saying, we recognise that here at NISCC and we are doing some work to try and overcome some of those difficulties.

But there is still going to be that major impact on the number of staff available. And we're also working with a couple of local councils, looking at how to reach unemployed groups, so working with Belfast Council specifically around setting up a skills academy next week for two weeks, and Omagh and Fermanagh Council who are going to be doing that as well. And we're doing a lot of work with the schools and colleges and looking at those specific areas. Just to let you know that we do know there is a block though, we do know that there's difficulty there, but we are certainly doing some stuff in the background.

R: I mean the reason – just to clarify as I said younger people, because there's this gig economy now, zero contract, zero hours contracts, and there are no kind of semi-stable employments. And even in something like social care where you can see the difference you're making would be an attraction for some people, despite the it's not easy work, it's difficult work, it's very emotional work and all the rest of it. But I can't, there's something wrong with, I don't know, it starts with education, because when you're in education I think they're pushed to get results, and the results are pushing them towards academia as opposed to vocational. So, there's a whole big system thing here.

R: I have that debate constantly with AFE [sounds like] because my main job is developing qualifications, and we have a debate constantly with AFE [sounds like] who want to develop the HNDs, the HNCs the extended diplomas, to push people into academia. We constantly are saying no, we need vocational, we need competence, we need the good people to stay with us. So, everything that you're saying is...

Int: Again this is very, very interesting discussion, and what I'm taking is in the context of economic and political crisis outside of adult social care, the impacts, and the context of not enough care packages and a growing pressure on the system to keep the good workers working in the adult social care. Some of the discussion on attitudes we've already discussed, my next question is very connected with that. In the context of all these pressures that you've outlined, do the disabled people fit the system, or does the system fit disabled people?

R: Neither.

Int: Okay that's a good answer. It's obviously a key question for us, and I know we have very little time, but even if you can give me your thoughts?

R: I would say disabled people don't fit the system, but they're expected to is more a way of putting it. That people are expected to fit into the system that's already there, I've had an argument with one of our funding inspectors shall we say, with an organisation who will remain nameless, who told me we had to write a risk assessment and a support plan about an event, and I pointed out that the person didn't want it, the event was over, they wanted to put it out of their mind, they didn't want it brought back up. "But you have to write this," and I went, "I don't have to write it. If the person in question wants to write it, we will write it with the person." "But you will do this," and I went, "I won't do this." Although there was a table between us, it had become very dangerous. But there is still an attitude out there that again goes back to, "You will fit into the system we have, we will not change our system to meet the needs of the clients, this is what we say you will do, and you will do it whether it fits or not."

R: I think there's that elements where you want to do the right – you want people that your supporting in the system [inaudible 0:31:32] managing it. But it's very easy to get frustrated with everything in these kinds of conversations and we have so many examples of where we can't do it, whether that's attitudes or systems based. But equally we all have really good examples of where actually service has been provided got spectacularly right, and when we get it right the difference that we make is phenomenal. So you know, you've got some questions about, you said earlier is attitude doesn't have to be negative, we have a lot of positives as well. So, yes there's all of those issues, but then there are times where we get it right, or it works, or we can implement a system and that improves the lives and the quality of life and the independent living choices for our clients. I think we all certainly have examples of those as well.

R: But we tend not to talk about those examples because everybody focuses on the negative stuff.

R: Because it's the wider issue, because that's the bit that we all struggle with, but we can equally celebrate some of the successes.

Int: **I can tell you that from our interaction with disabled people, they can also give examples of how attitudes have changed for the better, and the change of one attitude they say the tiny things that mean the world really do mean the world. And there is almost like a snowball effect in terms of improving services. But because this is so important, and yes, we do not talk about the good stuff enough, can you give an example of where an attitude has changed to enhance independent living choices? You already gave that one example in Scotland where from what I heard was we listened to them, we actually listened to them?**

R: We listen very carefully to the [inaudible 0:33:16] of the service, well they weren't a couple they were a brother and sister, but they wanted, we looked at the services they wanted to access, and we looked at how they wanted their care to be delivered and who they wanted their care to be delivered by. It wasn't as easy as it sounds, it took an awful lot of arguments, but they were worth it. And then the difference it made to their lives was phenomenal. I mean we're talking about attitudes, and I just remember the brother, they were both in their 70s and he had a handbag, and some jewellery that he really liked to wear with his initial team he wasn't able to do that, he felt very uncomfortable. I think somebody laughed at him.

But when he got his new team, they were able to understand him and respect him and they used to carry their belongings around in a bag, because they didn't want their care team to steal any of their precious things or see them or make comments. And within about two weeks of the new service going in, they stopped doing that, and all of the behaviours diminished, and he was able to take his bag and wear his jewellery. And other things we'd found that there was concerns that they were always wearing old clothes, and they were from that mindset or that generation where you wore your best clothes on a Sunday.

Then over a period of time those clothes became worn and then they kind of moved into the week, and they weren't getting the chance to wear their best clothes on Sundays. So, all of their clothes were deteriorating, so it was trying to understand what they needed, and then to give them those choices and those opportunities. But to understand and respect them, I think sometimes it's difficult with young generations when they don't really understand a post-war mentality, that this couple had grown up with, where you didn't throw things away and you reused things, and you did things in a certain way. And promoting and understanding that that makes a huge difference to the wellbeing and the trust within that service provider relationship.

Int: **So, this is an example where the system fits around disabled people to accommodate their specific desires, needs, we all have them. Can we talk a little bit more about whether or not disabled people have to fit in the system, or the system has to be moulded around their needs? What would you say?**

R: I think that's very difficult, and the reason it's difficult is because of the, everything's finite resource, and we do talk about person centred care and we talk about the individual being the centre of that, and about developing services for the person. We've talked about the resources that we have, we've talked about how difficult it is to get people moved from hospital back to their own home.

And I suppose services while they do try to provide a person centred service, sometimes they can't do it because they just don't have the resources to do it. And it's not that they don't want to do it, they just don't have the resources to do it.

R: It's not only that, it's also about knowledge about people's disabilities. I mean I have a son with autism and I also think, "God help him when he gets older," because there's so many people haven't a clue about how to communicate what life is like for him. We've all got people with dementia, what is life like for that person? And there's such a lack of knowledge that we still have to plug right across the service, right across society, and that's why we're chipping away, we're getting dementia friendly time, we're getting autism friendly centres, because we're chipping at that, we're trying to increase people's knowledge. But we don't have it there yet, so people don't have the knowledge about the disability to be able to help a lot of people, and that's a barrier.

Int: Okay, just to take it from there, if people don't have the knowledge on disability and presumably this also includes people in the context of let's say domiciliary care or at home care, that's the same actually, or in their context of a residential home or even a set of services, then if there is a lack of knowledge, and we already discussed the resource or lack of communication, then who ultimately decides what the needs are of the disabled person? Fair enough there are problems with resources, there are impacts outside of adult social care, the impact of what happens in the field, but how do we decide what people need?

R: Before anybody could get any regulated service, there's a full assessment carried out, and that's by the Domiciliary Team. If that's being done correctly that should be done with the client and the client being part of that. But that doesn't always happen. So from that [inaudible 0:38:49] assessment, there's a care plan developed, but we're moving more and more of that to support plans, person centred support plans, and that's about training people to look at things in a different way, about giving the person the voice. But I mean we're chipping away at that, we're ever increasing our training staff around what does self-directed support mean. There's been a push about trying to get more and more people to take personalised budgets, have self-directed support as opposed to residential care provision. As a society we're trying to increase that to give people more of a voice. But I mean we're not there yet.

R: Yeah, because you can see such a difference, because I know we use support plans, but you know, in the 10 years I've been working in this, because I moved out of residential and nursing care to support level and day care and that. But even from the [name] will, [name] can, [name] must and all that, to the I will, and I want to, and that is such a big difference you know, in that 10 years, where you have staff now looking and going, "Well actually I'm not writing this, the person's writing it." I might actually do the physical writing, but the person's telling me what they want.

And I suppose for younger staff coming in, they're learning that from scratch, so they haven't worked in the system where it was [name] will. So, I suppose sometimes with our established staff, that we never want to lose, but their attitudes are ingrained in the old models. And it's getting those attitudes for the older staff, "This is the way I've always done it, it always worked, why would I change it?"

So you know, we have found that we've worked well with new staff shall we say, not younger staff, new staff. And it's has taken us a wee bit longer with our established staff, just to get them into that way of thinking.

R: And it's difficult for people to have that change in attitude, it's difficult to move from...

R: Doing for.

R: ...doing for, it's very, very difficult and again I would say that from personal experience as well, my mum and my dad, you're constantly having to say to the people, to the carers, to the people who are coming in to help, "Can you instead of doing X, Y and Z, can we look at ...?" It's like moving a dinosaur up a hill.

R: And that [inaudible 0:41:41] advocate, what about the disability? A communication issue, perhaps autism, perhaps dementia, and they don't have relatives?

R: I know, are they going to strike me? I am actually very fearful of all that in me because I don't have children, I'm very fearful that will be me in another 30 years.

R: That's the attitude, everybody isn't [inaudible 0:42:05] supporting. It's not that we're all barriers the whole way along, and if you have a family who will advocate on your behalf that's great. But [inaudible 0:42:15] if they can't do that?

R: I know my mother-in-law was in the started in the residential move to the nursing home part of where I used to work. Which was funny because staff didn't quite know what I was there for. Staff who knew me from before didn't quite know what I was there for. And new staff were wary of me because, "How does she know all this stuff?" But we had one occasion while my mother-in-law was still walking, we were visiting and she said, "I need to go to the toilet." I says, "Oh come on," and I took her to the toilet, we were on our way back to the room, we met a member of staff who said, "Is there something wrong?" And I went, "No she was just needing the toilet." "I'll take her."

I goes, "No she's been to the toilet." "No it's my job and I'll take her." And I went, "She doesn't need to go anymore, she's been." And he goes, "But that's my job," and I went, "Yeah she's able to walk, I know what I'm doing, I was able to go with her, there's not an issue here." It was a shock to him that somebody, a relative could actually take somebody to the toilet. That's their job, "How dare you take my job." Then I said, "It's fine, I used to work here I know what I'm doing." Then it was, "Why are you in?" I says, "My mother-in-law." "Are you here to check on us?" And I went, "She's my mother-in-law, I'm here to visit." It was horrendous because the member of staff immediately became so defensive.

R: We're employing people into the care profession that shouldn't be there. We're taking people because we need to recruit, and I don't think it's right, and we think we can train them to do everything, you can't. If you haven't got the right mindset, and you want to help and you're compassionate, you may as well forget about it. Anybody can be taught to make a bed, anybody can be taught certain things and certain skills, and if you have somebody who cares and wants to do the best for each other [inaudible 0:44:15].

You do learn to balance here, you do learn to play here, it all matters, because we are paid a pittance for people to look after our citizens, and we expect them to work to the highest standard. It all matters.

R: You only have to look at the minute at the recruitment that's going on for I was going to say for one supermarket, but other supermarkets are available.

Practically every supermarket in the country has ads out on social media, and like the pay that they're giving people compared to what we're given... Yes well, the majority of people come into this sector because they do care, and they do want to make a difference to somebody's life. Nobody comes into it anymore to get paid because it just doesn't happen. You can go and stack shelves in one of those supermarkets and go home and forget about your job. Whereas most people in this job, yes, I would agree [name] we do have people who shouldn't be in, because we are short, and we take people that if we had a choice we probably wouldn't. But you know, people come into this, you can stack shelves and say, "Go home forget about it," this job you go home and you're still thinking about, "What about so and so, I wonder will she get through the night, I wonder if she'll be okay by the morning?" You do all that.

R: I mean if the weather's bad and there's the [inaudible 0:45:35] snow and our care assistants have to get out to that person or they're not going to get put back to bed or whatever. But as you say that's not...

R: Is the use of the technical skills as well, I mean the requirements have changed significantly. It isn't now just personal care, we're expecting people getting paid between £8 and £10 an hour to do trache gear [sounds like] and suctioning and you know whatever else is required for significant and complex care packages. So you know finding people who are prepared to take that level of responsibility because it's not just about the basics, it's about complex care where there is an inherent risk. And it's finding people who are prepared to do that with the pay that we're offering as well, it's challenging.

R: I think because our support with the service we're dual funded, and they expect patients from the two funders are so different, and they spend a wee bit of extra time doing one than the other. But you know, attitudes I know from the Supporting People side, most people have worked in care at some stage, or have been involved. Whereas we find with Supporting People they are housing people, they don't understand the care side the way they should. You know there's an expectation that, "Here's what we pay for and this is all you will do."

R: That's not what they're funding, you see they're funding the support, they're not funding the care.

R: Yeah, but you can't sort of – we always say you can't separate the two, even if you're only funded to do the support, you can't separate the two, because you can't turn around and say, "Actually I'm not paid to do that, so go and find somebody else to do it." Staff will go over and above. But again there's that expectation that staff will go over and above, and I think that's across the board more and more. You know you look at hospitals settings, it's over and above what you're paid to do, and most people will do it out of the goodness of their heart more often than not.

R: One example of a really positive move would be in one of our supported living schemes we have a gentleman who can only communicate through blinking his eyes. He came out of the nursing home because he didn't like it, he didn't want to be in a home. He's not a tenant in a supported living scheme and he loves it, and he can communicate with his eyes through to a machine, and he can tell us that he feels empowered, he's leading the life he wants. So there are terrific success stories about it, it's not all doom and gloom. So there are disabled people who have come into new models of working, you know from domiciliary or supported living, but they're not the normal, if you know what I mean? So there are some examples like that.

R: I think some of the issues around training I think for people with disabilities is empowering them to be able to communicate with people. Because like [name] I have children with autism, I've never worked in adult disability, but I wonder about going forward with my kids and the difficulties they have been listened to and put in education never mind anywhere else. So there's something about allowing and empowering those people with disabilities to help train the people that are working with them. Because I think you have to listen to the people with the disabilities more and more. Some things we get a lot of the training comes from the professionals, I think the training has to be inclusive with the people with the disability, otherwise I don't think people really get the sense of what it is. And if they can't do it, maybe their family and carers can do the advocating can be brought in to do that training to make the training meaningful.

R: But if you go to any conference, if there is a service user carer sat in the room, they'll be the people you remember, it will not be all the professionals that talk for seven hours out of the eight. It will be the actual people themselves who've experienced whatever it is that you'll remember at the end of the day.

Int: I think this is a great note to finish the conversation on, that disabled people's experience will be the one that will really make an impact, and if we can integrate disabled people into the training for adult social care, that might make a really positive change. We've run out of time, but the discussion has been to me fascinating, there is so much more we can talk about. It's a huge topic and we're aware 45 minutes is only scratching the surface. But we just want to thank you for taking part in the focus group and sharing some of your thoughts and knowledge. Yes, it's been a very informative conversation for us to see the different perspectives on these issues. So thank you all very much.

[Close]

'Is It Me?' Attitudes, disability, independent living and a...

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Disability Research on
Independent Living & Learning

'Is It Me?' Attitudes, disability, independent living and adult social care

Please read: About this survey

This survey is for social workers and social care workers from across Northern Ireland who work with disabled people. We want the research to include people doing different jobs (domiciliary, day care, residential) for a range of providers (private, voluntary or Trust).

We would like you to answer the following questions in the survey. Most of them are answered by ticking a box, and there are a few questions that you can answer using your own words. The survey will not take more than 10 minutes. You can save your progress, exit the survey and come back to it later.

There are no risks to taking part although some of the questions may make you think about times you have seen someone being treated unfairly. The survey is completely confidential and there will b no questions regarding your identity or geograph location. Although it is possible to trace people through their computer IP addresses, we will make no attempt to use this information. In accordance with Data protection policy, you can request our Privacy Notice by emailing Fiona McMahon (DRILL Programme Officer) at fionamcmahon@disabilityaction.org.

We will not ask for your name or for any information that shows who you are. No organisation, including NISCC, will be

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the experiences disabled people have when accessing independent living choices in the adult social care system.

We will publish survey findings in a research report. the anonymised data from this survey will also be published on the UK Data Archive for the use of other researchers. If you have any questions, please contact: fionamcmahon@disabilityaction.org

How can I contact the research team?

Please call the DRILL researcher Darlene Corry on 028 9029 7880 or email her at darlenecorry@disabilityaction.org

* 1. Consent (Please tick all to continue)

☐ I have read and understood the information above.

☐ I understand that no one will know I have taken this survey.

☐ I am happy to take this survey.

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'Is It Me?' Attitudes, disability, independent living and adult social care

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2. Do work with people with disabilities?
(This could be within any service delivered to

adults, for example, older people, family services, etc.)

○ Yes

○ No

3. **Theme One: Awareness of independent living choices**

Do you think that disabled people using adult social care should be informed about independent living choices?

○ Yes

○ No

4. Do you think people with disabilities receive
enough infor
choices in the
system?

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○ Always	○ Rarely
○ Usually	○ Never
○ Sometimes	

5. Please rank as No 1 the person or group with the most responsibility to provide information on independent living choices for a disabled person in the adult social care system, through to No 5 for the person or group with the least responsibility.

≡ Social worker

≡ Social care worker

≡ Family member

≡ GP/health professional

≡ The disabled person themselves

6. **Theme Two: Stereotyping**

Can people with disabilities be independent in their choices?

○ Yes

○ No

○ Please tell us in your own words or give examples.

7. Do all disabled people have the same needs?

○ Yes

○ No

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○ Please tell

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8. How important is it to keep asking a disabled person questions regularly when assessing their social care provision?

○ Unimportant

○ Neither important nor unimportant

○ Important

○ Essential

9. **Theme Three: Lived experience of disability**

How important is using professional experience of what has worked for other people in relation to independent living choices in the adult social care system?

○ Unimportant

○ Neither important nor unimportant

○ Important

○ Essential

10. Who has the most knowledge about independent living choices for an individual

independent living choices for an individual disabled person? Please rank No 1 the person or group with the most knowledge through to No 5 as the person or group with the least knowledge.

- Social worker
- Social care worker
- New version available!
- Saving changes...
- The individual person with disabilities themselves

11. **Theme Four: Continuity of care**

How important is it for a disabled person to have an ongoing relationship with their social care worker or social worker?

○ Unimportant

○ Neither important nor unimportant

○ Important

○ Essential

12. How important is for the social care worker or social worker to communicate any changes in a care plan?

○ Unimportant

○ Neither important nor unimportant

○ Important

○ Essential

13. How important is for social care services to be

13. How important is for social care services to be provided at the time arranged?

○ Unimportant

○ Neither important nor unimportant

○ Important

○ Essential

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14. Is the time given to the care of disabled people sufficient to address independent living choices? (For examples, in setting up care packages or domiciliary care.)

○ Yes

○ No

○ Don't know

15. How much does funding impact on independent living choices?

○ Does not impact at all

○ Impacts a little

○ Impacts a lot

○ Impacts significantly

16. **Overarching theme: Attitudes and independent living choices within adult social care**

What attitudes do you think people with disabilities experience generally in the context of independent living and adult social care? This includes from those delivering the care and the management of the service.

○ Very positive

○ Positive

○ Neither positive or negative

○ Negative

○ Very negative

Please tell us about this in your own words

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17. Does the a facilitate independent living choices for disabled people?

○ Yes

○ No

18. Should there be more independent living choices available to people with disabilities in the adult social care system?

○ Yes

○ No

○ If yes, please tell us what choices should be available.

19. Is the person with disabilities required to ‘fit in’ to the adult social care system and what is available?

○ Always

○ Usually

○ Sometimes

○ Rarely

○ Never

○ Please give examples of what is available.

20. What are most important values for staff to have in facilitating independent living choices for people with disabilities in the adult social care system? This includes from those delivering the care and the management of the service.

Please tell us

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About You

Please answer a few questions about yourself. These are to make sure that we know more about the social work an
completed the

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21. Do you identify as a disabled person?

○ Yes

○ No

○ Prefer not to say

22. If Yes, what best describes your disability? Please tick any that apply.

○ I do not have a disability

○ Sensory impairment - visual/sight

○ Sensory impairment - auditory/hearing

○ Deaf

○ Learning difficulty

○ Physical impairment

○ Mental health condition

○ Long term health condition

○ Other

○ Prefer not to say

○ If Other, please describe your disability using your own words

23. What is your role in social care?

○ Social care worker

○ Social worker

○ Student / trainee

○ Other

24. Which sec

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○ Public (Tru

○ Private

○ Voluntary

○ Combination of the above

○ Other

25. Where do you work?

☐ Community

☐ Hospital

☐ Health Centre

☐ Prison

☐ Probation

☐ Other

☐ Domiciliary care

☐ Day Care

☐ Residential care

☐ Family support

26. What kind of geographical area do you work in?

○ Rural

○ Urban

○ Rural and urban

○ Other

27. Are there any other comments you would like to be included in the survey?

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Thank you very much for completing this survey.

If you have any questions, please contact Darlene Corry from Disability Action NI on darlenecorry@disabilityaction.org or phone 028 9029 7880

28. Please enter any comments on the survey here

⊕ NEW QUESTION ▼

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