[0:00:00]

Interviewer: Okay, [Name 1], so you started by explaining that you're not currently working with people with Huntington's disease. So, can you tell me a bit about the work you're doing currently?

Respondent: Yeah. So, I work for [Location 1] Council and I'm a learning specialist in adult social care. So, my remit is to work within the learning and development team for [Location 1] Council and we work mainly with internal staff members in terms of updating them on anything that comes within their remit within adult social care. So, mostly safeguarding, domestic abuse, but I also take responsibility for providing some learning and development in long-term conditions within [Location 1], Huntington’s being one of them because of my background and the contacts that I had with various organisations. So, we've set up an information repository for staff to access information on things like Huntington’s and Parkinson's and multiple sclerosis and motor neurone disease and diabetes and things like that. So, day-to-day my responsibility lies within training and learning and development for our staff groups. So, a whole range of things. But no longer focusing specifically on neurological conditions which I have done in the past.

Interviewer: And this training is accessible through a website, through a learning portal or…?

Respondent: Yeah, we use a learning portal within the local authority, but we also provide learning and development directories. So, we make sure that external partners have access to particularly the safeguarding and domestic abuse agenda that we focus on within the local authority. But we also do routine stuff like moving and handling and medication awareness and induction training for new staff. Just whatever adult social care staff might need.

But in addition to that, in the wider sense, because we're a local authority and have responsibilities right across the board, I'm also involved in disseminating some of our safeguarding training to housing and construction staff, frontline staff out in the borough, you know, and kind of street wardens, that kind of thing. So, yeah, it's a very varied, interesting kind of learning and development focus within [Location 1].

Interviewer: So, the stuff you have accessing the, like the portal specifically, are what, people from private companies as well or not so?

Respondent: As well. Yeah, we do have some external partners who would be care providers or care agencies or housing. Mostly we've got local authority housing rather than private housing. So, we have a really good internal team of housing, sheltered housing staff, who provide housing for older people under the [Location 1] Living banner that we have within [Location 1]. I would say the majority of our customers are internal staff, so assessment staff as in social workers and community wellbeing officers, but also looking at, as I say, housing, housing and construction, home care teams, just anybody who needs to know about the things that we want to tell them about. So, it’s busy. There's a lot.

Interviewer: Wow, yeah. I mean that sounds like you're running like a university.

Respondent: Not quite. It's not quite like that. And I think that we've got, obviously we've got some mandatory training that people have to have access to and then a lot of our learning and development offer is kind of the extra icing on the cake. So, certainly the long-term hubs thing, I would like it to be mandatory for people to learn more and understand more about long-term conditions, but we accept that we've already got a range of mandatory learning that they have to engage in.

So, we offer that as something interesting that they can learn a little bit more if they're working with somebody with Parkinson's or somebody with Huntington’s. My view has always been the more we can get awareness out there and get people to understand the complexities of the range of neurological conditions that people might be affected by, the greater the chance that we might hook them in, just as has happened with you in terms of your initial interest as a nurse has led you into that areas of neuro interest, and that people will have a greater awareness of how complex these conditions are and how we can't just look at one clinical symptom. We actually have to look holistically at an individual and see what can be done for them and with them to improve their situation. I think like everybody in this field I've come across far too many people who've been knocked back in terms of benefits assessments, who've been denied access to the services that they ought to have access to and who have hit a wall of ignorance really in terms of what Huntington's or Parkinson's or motor neurone disease might represent to them. So, the more we can raise awareness, the better.

Interviewer: This is great because you’re working from the inside, isn't it?

Respondent: Yeah. I was just going to say, so I started, my kind of history over [35-45] years is I started with [redacted indirect identifiers, subject has work experience in different care contexts, different neuro-degenerative conditions, and sectors, across different locations] (…) So, I've got a really good kind of spread of lots and lots of knowledge and experience over all that time. And it just, I feel like every day I kind of bang the drum for person-centred care and it's weird that over 40 years we seem to be taking backward steps rather than forward steps in that regard, which is very frustrating, but…

Interviewer: Yeah. So, but you thought you wouldn't be a good fit for the study. Look at that.

Respondent: I know. Well, no, I just felt it was, you know, my kind of initial thoughts when [Name 2] had got in contact with me and I'd responded to you was that you probably wanted somebody who was still in the thick of it. And I don't feel that I am so much because I don't have that kind of immediacy at the moment…

Interviewer: Yeah, but you have worked in different sectors and you have worked with people that are vulnerable, not just neurological, but in other cognitive senses and social senses. And you are part of the, like you're trying to reach the workforce so actually you're a pearl, as I said. So…

Respondent: Oh well. Thank you.

Interviewer: For me it’s really good. Okay. So, [Name 1], you were saying, I mean you’ve already touched here in so many of the difficulties, but you were saying you realise how difficult it is for people to get access to the benefits or to the help due to ignorance, okay. And this one of the findings from my previous study, which is a lot of the people that are involved in caring for Huntington's families are not knowledgeable about Huntington’s. Which again, it's a bit like with the GPs, social workers cannot know about every single condition. GPs cannot know about every single condition. But, and this, you know, for me, I really wanted to speak to someone that had some insights into social care because what I was told was that if someone needs assistance they ring a switchboard and then switchboard says someone will contact you. So, then they get a contact. They're contacted by a social worker, for example, or a social worker comes by home and has the discussion or a plan or something. But then basically, as soon as it's minimally resolved, the person gets discharged and when they need something else, like in a month’s time, they ring switchboard, a different person gets allocated. Is that the experience you have with it?

[0:10:35]

Respondent: That’s absolutely the experience that we have. And interestingly, when I worked with the [specialist voluntary organization] in [Location 3], I worked very, very closely with our regional neuropsychiatry team which were based at, initially they were based at [Location 4], which is a psychiatric hospital that we had. We no longer have it. Well, we do, but it's very minimal.

Then they had moved to [Location 5], which is where Huntington's kind of specialism, clinical specialism, is provided within [Location 3] way, way back. And I am talking… I worked for Huntington's between [redacted], so that was over a ten-year period. And way back then we had a philosophy and we very much worked towards once you're in the system, that's it. You don't leave that system. You’re kind of supported by that specialist team, that regional specialist team. And I was kind of co-opted into that, although I was in the voluntary sector, I was still involved in terms of some of the assessments that we were undertaking and some of the family work that we did and we established that, there was a need to work with younger members of Huntington's families and younger people who had juvenile onset Huntington’s.

So, I got involved during that time in providing, we did summer camps for kids and we did specific juvenile onset sessions for kids. There's no, within the [Location 3] there's a specific juvenile focused, like a youth worker for younger people with Huntington’s. So, it was very much a kind of grassroots view that we did. We took a holistic perspective and we worked with people all the way through the process so they were never discharged.

And I think that one of the great difficulties that we have, because of course social care, adult social care has gone through many iterations during my [redacted]-year experience of working in health and social care, and we do have people who have to meet, in some circumstances, they have to meet eligibility criteria. You're absolutely right in [Location 1] we have a contact centre where new people would come via phone or via online queries. They're initially having conversations with our contact centre staff and then depending on whether they meet eligibility criteria under the Care Act, that's when they would be allocated to a social worker or a community wellbeing officer to undertake that assessment. And getting our staff to be aware, both our lead practitioners and our frontline staff, to be aware of the need to have ongoing contact with people when they have a progressive condition is one of driving forces.

So, I would say probably in our local authority we, I’m bound to say this, aren't I, we have some awareness of how important it is that you don't just open a case and close a case when one issue has been resolved. But it's very, very difficult because there are pressures on social care staff to be able to deal with new cases coming through. We have capacity issues like everybody has. We have a social care crisis which everybody's experiencing in terms of retaining staff and recruiting staff. So, it is, it's a pretty difficult thing, but we try wherever possible, we try to make people (staff) aware that with a condition like Parkinson's or Huntington’s or motor neurone disease, we need specialist information and we need people to stick with the individual as much as they possibly can so that they're not just discharged.

We also, as is common with lots of local authorities currently, we are really committed to working in strength-based ways and trying to have a partnership approach with any individual that we're engaging with. So, we've done lots and lots of work with our staff teams in terms of strength-based approaches, in terms of looking at asset focused work rather than deficit focused work. So, it's all part of the bigger piece, but it does feel like you're, well, not just me because I'm not on my own. We're a very small team in adult social care for learning and development, but we're chipping away with tiny, tiny little hammers, trying to make people aware. And there are so many other kind of constraints and pressures on all of our staff teams.

But yeah, I think you’ve hit the nail on the head. That's essentially what might happen is that people will come with an issue, the issue will get resolved and then the case might be closed. What we're trying to look at is a much more outcome focused way of working with people where we, according to the need that they have and if they meet the eligibility criteria, that we actually would keep a case like somebody with Huntington's disease, we would keep that open and allocated to a specific worker. But that's easier said than done in some ways.

[0:16:08]

Interviewer: Yeah, but for me, even in trying to be pragmatic, and I mean, I understand in terms of figures, people are again you're saying like pressures to reduce the load, but then again are we, it doesn't feel like to me that we're reducing the load. Maybe in terms of figures we are, but actually, if you look at it long-term again, these people, their needs only become more complex and it just seems to me much easier if we have one person that then maybe, not aware of the disease, but with the contact with the families then become aware. Or that families with these conditions are signalled to, linked with always the same professional that is aware. So, it just seems to me that even in terms of cost and everything that it just… so, I personally struggle to understand how this is easier or like that we're streamlining because it just makes, it sounds like we're sweeping under the carpet. That's the feeling that I get.

Respondent: And I feel, you know, there's a thought of, “Oh yes, that's that”. You know kind of rare condition that hardly anybody gets, ergo there's little investment in terms of working with people who have very complex conditions like Huntington’s. And if there isn't that awareness of how difficult and complex this can be, and also, the other point that I have to stress, which I don't need to stress to you, but we're not just talking about one individual in a Huntington's family. We're talking about that ripple effect, not just with Huntington’s, with Parkinson's as well, but when we factor in the familial element, the psychiatric and mental health impacts for families who are at risk of inheriting the faulty copy of the gene, the impact that that might have on their decision-making just in terms of the relationships they get into and the choices that they make in life, you know, maybe in terms of alcohol dependency or drug dependency, we’re looking at a much, much bigger issue.

The problem I think that we've got specifically with Huntington’s is because it's perceived to be a rare neurological condition and the numbers that we're actually looking at are relatively small. So, if you look at that kind of 8,000 to 10,000 people across UK, the assumption is, “Oh, that's a tiny, tiny amount and we don't need to really consider that because we've got all these other issues to deal with”. But in actual fact, if we can raise awareness and make people aware of the complexities of the condition, you're right, in a kind of future proofing way, they'll have a better understanding of why we need an allocated individual who's up to speed and understands the condition.

So, yeah, I feel like it's a quite a Sisyphean task, if you like. But it's something that we have to keep on chipping away at in terms of people's awareness and staff awareness of the importance of continuity for people. And that level of trust so that they can build up a working relationship with somebody and know that they're going to respond appropriately, that they're not going to be shuffled from pillar to post for each issue that comes up. But yeah, that’s a big one, which is why I think in the [Location 3], we're really, really lucky in that we have a good team now based at [Location 5] and that people do have that that sort of throughout of journey so that their contact in [Location 3] will be with the [Location 6] in terms of genetic testing and pre-genetic counselling, pre-genetic testing counselling. They then will have involvement with [Location 5] when they become symptomatic and they experience some of the difficulties that they experience.

And then within community teams in [Location 1], in [Location 7], in [Location 8], in [Location 9], there’s a kind of feed into the expertise that's housed within that regional team at [Location 5]. So, in the [Location 3] it possibly is maybe better than in some other areas of UK, but I couldn't really comment because I don't have any experience really elsewhere. It's just within this area within [Location 3] that I have some awareness of.

Interviewer: So, when you said earlier that you think we took a step back actually as in things are getting worse, not better, what were you thinking of?

Respondent: Oh, just generally in terms of the current cost of living crisis that everybody's experiencing within UK and possibly elsewhere, it seems to have really kind of pared back the level of services that are available and over the past 14 years of the current incumbent government that we have, I would say we have less opportunities and less care provision. It very much more feels like you’ve got to fight for any kind of service level that you might get for a particular individual that you're working with. I mean, in UK at the moment, they're talking about, this doesn't relate specifically to this discussion topic, but they're talking about cutting access to benefits to people with mental health difficulties because there’s assumption –

[0:22:19]

(Overspeaking)

Respondent: - and the assumption seems to be that everybody's winging it and pretending that they're ill when in actual fact they are experiencing very real levels of anxiety and depression and various other mental health issues exacerbated by COVID and lockdown, which we've kind of come through allegedly at the other end off, but I don't think we've dealt with all of the challenges that we had during COVID effectively.

So, for that reason, I would say when I speak to our staff teams, our adult social care staff, they really feel they are working incredibly hard and they are not achieving as much. There aren't as many community groups out there. There isn't as much community support. When we talk about strength-based approaches in the way that we work, we rely on a network within the community and what might be available within somebody's informal support network. And a lot of that's eroded over the last four years or so, because of COVID, because of lockdown, because of cutbacks. We used to have, and because I'm quite old, I think back to 15, 20 years ago, we had Sure Start programmes, we had youth programmes available, we have community support networks for young people. We now have a situation in UK where there's no Sure Start, there's no youth clubs, there's nothing for kids to do. We've got a crisis with knife crime. We've just had [n] incidents in the past couple of weeks in [4 locations redacted] funnily enough this week of people being attacked by knives. And the general kind of feeling is that because young people have got nothing to do, gang warfare, exploitation, modern slavery, trafficking, all of that kind of thing is becoming much, much more endemic and so people carry knives because they feel unsafe and as a result of carrying knives if they get into any kind of a spat with somebody, it escalates and becomes a really dangerous situation where people have lost their lives, young people have lost their lives as a result of knife crime. And I'm going completely off-piste here, I'm sorry.

Interviewer: No, [Name 1], I think it's not off-piste. It’s the root of the problems which are not just Huntington's disease specific, it's societal, cultural.

Respondent: It is. And what happens is, if you don't have a rich, diverse society that supports one another and recognises vulnerability, you end up, as I perceive we are in 2024 in UK, with a kind of cut throat, dog eat dog culture and caring gets marginalised so it becomes, for the more vulnerable people, they get pushed more and more to the sides. And that’s kind of the root of where we, I feel, we don't have a safety net. We don't have what I would perceive as being a supportive framework for people who are vulnerable. And it's not just about people with Huntington’s. There's a load of people out there who are vulnerable, but because they're not properly supported, then it’s just so much easier for people to fall through the cracks, to fall through that very patchy safety net and to find it harder and harder to access the support that they need. And if we have a culture, a blame culture, where people are vilified for experiencing mental health difficulties or experiencing neurological difficulties, if there's a lack of awareness and a lack of understanding, that's where you see exploitation and the lack of care taking place. So that's, in a nutshell, that's my view of society currently is we're much less caring and consequently we are failing in our duty of care I think to look after anybody out there. And when it comes to people who have increasing vulnerability, it's just harder and harder for them to access the help and support that they need.

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Interviewer: [Name 1], with the groups, like I've attended the Sure Start groups with my toddler then, and all these groups and I mean, where is the money going if it's not going to these groups anymore? Where is the money going. Where is that money? You know, where is it being repurposed, I mean, I'm not saying you should know this, I'm not saying, I'm just…

[0:27:25]

Respondent: No, no, no, but in my cynical head you could say, and there was, you know, at the point where we changed our political focus ever so slightly around about 2010, we’d just come to a massive financial crash in 2008. In 2010, we had a change of government within UK. There was a lot of vilification about how much money had been spent in the previous government, which was a Labour government from 97 to 2010. So, there was a lot of talk about how money had been wasted and people had been given money that they shouldn't have had access to and benefits culture had increased and all of that sort of thing. We went into a period of austerity from 2010 onwards. And really, between you and I, what I see is any money that there is seems to go into the pockets of individuals who are getting richer and richer, whereas the people who really, really need support and help, and I'm encompassing education, social services, hospitals, the NHS, community groups, you know, kind of community support, nobody in any of those areas it seems to be getting access to the funding that they need to do the job that they need to do.

So, yeah, I mean that’s a very cynical and very narrow view that the money seems to have been diverted from a societal cultural support network into individuals who've profited. But that's kind of where I think it's gone. And if you think about, you know, when we hit COVID in 2020, there was a knee jerk reaction right across the board in terms of, “We need PPE,” and that's where people, individuals, really benefited from putting in scurrilous claims that they could provide PPE and then they were providing really substandard equipment and substandard masks and aprons and gloves and –

Interviewer: I was putting my gloves at the hospital, already coming with holes. I mean, they were already coming with holes like.

Respondent: Yeah. And in 2020 I was working as a social worker in [Location 1] at that point and we had to go through a risk assessment for any community visit that we did. A lot of our work was being done through Teams, which was fine up to a point, but it's really difficult to assess capacity or to assess somebody with dementia or communication difficulty when you're on a screen. So, we would go out and see people face to face with a mask on which was even more difficult. And like yourself, I was pulling on gloves and as you pulled on the glove, literally your fingers went straight through and that provided no protection whatsoever.

So, yeah, I think that we’re in a, going back to the previous phrase that I used, it very much seems to be a dog-eat-dog kind of culture where people are vilified for being vulnerable and having challenges and difficulties and there seems to be less understanding. And in that situation, unfortunately, as I said to you before, [Name 3], I do a lot of safeguarding awareness and domestic abuse training sessions and we do lots and lots of work with all of our staff groups and our partners in raising awareness about vulnerability and exploitation. And what we see is that people out in the community are in a much more vulnerable position in terms of financial exploitation, in terms of cuckooing, you know, having their homes taken over by people who are running kind of drug exploits and that kind of thing. And it just feels like a not very caring society which it might be, it could be my age, it probably is, but it feels like over time we've kind of slid downhill instead of providing people with care and support that’s given in the way that it should be given. You know, I've done a number of home visits where somebody will have said, “Oh, and this my neighbour and they do my shopping,” and you just have a sinking feeling of actually, are you doing the shopping because you're a nice person or are you doing the shopping because you're getting some kind of benefit out of that or you've got some kind of financial interest in this very vulnerable individual who thinks that you're being really nice to them? But yeah, so, that's, as I say, in a nutshell, that's where we're at in 2024, I think.

Interviewer: Well, I was quite impressed, last week I was in [Location 14] for a conference on integrated care and one of the speakers was showing, I think it was from the Nuffield Trust, so they were saying how much money has gone into health and how much money has gone into social care through time. And England was the only country in UK to put more money, increasingly more money to health and decreasingly more money, well, less money into social care. While we're always speaking about bringing care into the community, keeping people at home and all of that, unfunded. As in so the money isn't really going into that purpose. So, what we are, I mean, with the survey I did, what I'm seeing is that, well, people don't want to stay at home for long as possible if they're not well taken care of at home, or if they're forgotten and left to it. So, what I mean… we're going to be quite depressed after this chat.

[0:33:29]

Respondent: (Laughter) I already feel quite depressed, to be honest. It's…

Interviewer: Well, yeah, me too, because I get the sense, of course, you know, I'm doing this project and my research is very much focused on Huntington’s and, as you are saying, no one's going to put any money on it because it's a rare disease. So, I'm quite realistic on the need of showing the common problems and solutions across other prevalent diseases so that because again I have people with Parkinson's telling me, “Well, but I have Parkinson's and that's the same, you know, that's the same issues I'm experiencing”. So, of course it's exacerbated in Huntington’s for the psychiatric, for the family, for being rare. So, it just makes the problem bigger or more visible. But as we're saying, it's not condition specific.

So, if we look at what could help in terms of feasible help, because we can say, well, we need a change of government and we need our decision-makers to commission the right things and the money needs to flow in a different way. Yes. But that's quite high level.

Respondent: It's enormous and macro and unfortunately, when I first started working with people with Huntington’s, it was just at the point that we got access to the predictive genetic test and I came into this area of work in Huntington's and everybody was so excited and the feeling was within five years nobody will have Huntington’s anymore because we'll have screened it out and we'll have a cure. And I was talking to, so as part of the work that I did in developing the information for the long-term conditions hub, I had spoken to key individuals from Parkinson's UK, from Huntington's Disease Association, from the Motor Neurone Disease Association and from the MS Society. And I can remember speaking to the then specialist advisor for the [Location 3] and he'd said we’re so near a cure, a cure’s just around the corner. I thought crikey, 30 years ago, we were saying we're near a cure, you know, genetic testing is going to screen this out. “We're near to a cure”. It feels like we're constantly chasing that elusive cure. And I think that within both the Huntington's and the Parkinson's communities, we have long said that it's not until you have either high profile individuals who have the condition and really raise the awareness because they are experiencing those difficulties themselves, or you have a wholesale change in philosophy which brings in the investment that's required in terms of drug trials and in terms of an approach to cure for any of these conditions, that we'll see any kind of a change. And that's, you know, you’re saying you want a pragmatic answer. I don't have one. All I can do is with my tiny, tiny little ice pick hammer is chip away constantly trying to lose –

(Overspeaking)

Interviewer: Well, but what you are trying to do is already an intervention per se, which is what you're trying to do is to get your workforce more aware and better knowledge, knowledgeable, sorry, about these conditions. You're creating training resources that they can consult. And again, you're saying you're working from a strength-based approach which is like, yes, we have, we're half the team we should be and well, but sort of like capitalise on each other's strengths. So, I mean that's what I'm getting from you, but as you're saying, you know, you're with your hammer pick. You're working at trying to make an impact at the level you can reach, and it's still quite a difficult task.

Respondent: It is. And I think we're all of us within the field of health and social care, we all of us have to make as much of an impact as we can make and that can be quite a challenge. It feels to me like it's very much a micro effort to do that chipping away. But actually, it's about creating communication, it's about creating awareness, it's about working with other organisations. So, I've really promoted the partnership approach with health that we have here for Huntington’s, for Parkinson's, for motor neurone disease. We have specialist teams throughout the [Location 3] for all of those conditions. But also, encouraging our staff within [Location 1] to be aware of the fact that we've got a great resource in Parkinson's UK, a fantastic resource in the Motor Neurone Disease Association, in the Huntington's Disease Association. The new regional care advisor, sorry, specialist care advisor who's just started with Huntington’s in the [Location 3] formerly worked with us in [Location 1]. So, that again, that's just another little connection that we can kind of tie our staff into that that sort of connection with [Name 4], who's just taken up post.

[0:39:06]

So, yeah, we just have to keep on chip, chip, chipping away and doing the best that we can. And that's really all that we can do. And I think that my job when I worked for the [voluntary sector organizations in neurology], my job was very much about raising awareness and providing information and sharing, learning and creating those connections between organisations. And I guess that’s sort of the work that I've done and what's taken me back into doing what I do now. So, it feels like I've come full circle from a learning and development point of view. But I don't, like anybody else, I don't have a magic answer because there isn't one. It would be interesting to see politically where we go within UK and whether there's any kind of a change that takes place. I sense there is (Overspeaking), well, I sense there's –

(Overspeaking)

Interviewer: For the best, I hope.

Respondent: Yes. I know, I sense that there's a great deal of dissatisfaction, but does that take us to an actual point of change? Because what I see is we have adversarial politics in this country and we spend an awful lot of time listening to people shouting at one another but not a great deal of time, listening to some purposeful communication and actually getting to a point where we see good outcomes for people. And just going back to the point that I made before, my feeling is in times of stress and difficulty, what you don't see is people pulling together. What you see is people protecting themselves and pushing more vulnerable people to the sides and people with Huntington’s are very much, I think, affected by that. I think they have, I can't say that they have a worse experience than they had previously, but it feels to me like it's harder for people with Huntington’s to gain access to what they need for lots of reasons, just because resources are scarce because it's difficult to allocate people who know what they're talking about, it's difficult to put people in contact with those who really understand the condition. And for me knowledge is the key to everything. If we can improve understanding and awareness, then we’re getting somewhere towards people really getting a condition like this and doing what they need to do.

Interviewer: Do you think that, I mean, do you have any connection with higher education or with social, the degrees of social workers, like you know, do you teach at higher level or no?

Respondent: I don't, I don't currently. I mean we do within our local authority we've got really, really good connections with the universities within the area and we have a steady stream of newly qualified social workers and placement social work students coming in to work with us to make them aware, generally, of adult social care needs within [Location 1] and children's services as well. But I don't have any contact with those institutions currently, just for lack of time really. My time is fully taken up with the day to day.

Interviewer: Yeah, it sounds like you're, yeah, because my, yeah, I was wondering if in terms of education and again, you're sort of like influencing the future workforce, if the content of the degrees are good enough on preparing people?

Respondent: Well, I think that it’s really, it's an interesting area, isn't it, because we were talking about doctors, general practitioners, having to really have an awareness of a wide range, a very thin smattering of a wide range of different conditions that might affect people. And social workers are very much like that and social work degrees are very much about focusing on the essentials they need to make students aware of the importance of safeguarding. They need to make students aware of the importance of capacity and decision-making and that whole kind of area.

[0:43:39]

But I think that our newly qualified social workers, when they come into post, it’s a little bit like a baptism by fire when they come into a working role as an adult social, social care social worker because there are so many plates to spin for our social work staff. And I think, yeah, I mean, I think there's always room for improvement right across the board, not just in social work degrees. You know, when we think in terms of the work that I'm doing within our team for learning and development for adult social care, there’s always areas of improvement that we could do more, we can dig deeper, we can provide more information, and we're constantly kind of revisiting our learning offer and our learning programmes to try and make sure that we're really hitting the mark. But that's quite a task as well, so…

Interviewer: Yeah. No, I was asking because, again, in terms of mindset and culture and I get the sense that a lot of staff may not know what the disease is, but also they won’t look to find out. And again, it could be because, well, they just sort of like do the minimum because you need to move on to the next case. So, one of my participants had suggested would it not be easier if we had again one social worker, even in the region, sort of like as we have the Huntington’s as these advisors to have our PIN like social worker PIN that knows of the condition that can consult with other teams.

Respondent: Yeah, yeah.

Interviewer: Does that exist?

Respondent: Not to my knowledge. I mean within, as I say, within the regional team from [Location 5], they certainly had previously. When I worked with [Name 5], who was the neuropsychiatrist, and I'm going way, way back, this like [20-30]-years ago, but his team had a specialist social worker, a specialist nurse, two specialist nurses, actually. One was a CPN, the other one was a medically qualified SRN. And then I was attached to their team as well in a slightly detached way. I don't know what they have. I know that there's a Huntington’s specialist nurse, but I don't know if there's a Huntington specialist social worker as such. And my go-to is the regional team from Huntington's Disease Association. So, I would always get in contact with the specialist advisor if there was a query that came up from one of our staff members that I couldn't respond to or answer myself.

But I think you're right. I think that the key to this having awareness about the condition and really committing to that need for continuity that people with Huntington’s have because you don't want to keep on telling your story to different people when you've got a communication difficulty and all of the other problems that we know that people with Huntington’s have to deal with. And then you kind of match that with the psychological impact of being in a family at risk, having to think about whether you're going to test or not test, what the implications of that are for your family planning decisions, for your relationships, for everything, for your working life. You know, it’s just it's a huge burden for them to have to deal with. So, if we can make it easier, yeah, that'd be great. But it's about that kind of commitment, isn't it, in terms of having. And I think that would be great. You know, if you had one individual who oversaw the need to pass on information and link people together and kind of undertake those assessments and pass on that assessment information, that would make life an awful lot easier, wouldn't it?

Interviewer: Yeah, I mean, I'm trying to put myself into the shoes of being a junior newly qualified social worker and getting handed over a case of a family with Huntington’s and if I could type in my system Huntington's disease and say in your area this is your social worker, expert in Huntington's, link with them, what a relief.

Respondent: Oh gosh, absolutely. Because it’s overwhelming and it's frightening. And when I worked within the community-based team in [Location 1], the last case that I worked on prior to coming into learning and development was somebody who had quite a lot of challenges, but because I knew about Huntington’s, I could kind of put those blocks in place and knew what we needed to do. And then when I had moved, because that's what people do unfortunately, and the case was to be allocated to somebody else within the team, there was a great deal of anxiety and I had said, “Well, I'll kind of hang on, I'll still be involved,” because it's not like I was moving authority, and I'll just pass on any information that I can in terms of whatever we needed to do with that particular individual. And it was it was relatively straightforward. It was about looking at some community based respite and looking at respite breaks for his wife. And I continued doing that for six months or so until that piece of work had been done.

[0:49:37]

But then, as you say, you know it's when that piece of work's done that just gets closed off because that's been done and it's been completed. What really should happen is that that individual should stay live in the system. But we don't really have the mechanism to do that always. We don't kind of close cases unnecessarily, but again, if you don't have that level of awareness of how Huntington’s affects an individual and the family and the carer and everybody else who's involved, your instinct would be, well, I’ve done the respite bit. That's it. Close it off. And then they'll come back to us if they need anything else. But I'm not involved in that. And we have, it’s not for data protection, well it is, but as a non-practitioner I no longer have access to our central recording system, so I can’t, I wouldn't anyway, but I couldn't look in to see what's actually happening with that individual and I don't have, because of confidentiality and that kind of dignity and respect thing. I wouldn't have access to any of that information to see what's going on.

Interviewer: But when you were in the system, you could see the records of the previous colleague within that individual, you can see the, I mean again, you need to take the time to read through the notes, which is what we don't have, but it's logged into, it’s installed in the system. Yeah, yeah, yeah.

Respondent: And I mean every contact that our frontline staff have, even if it's not an open case, if we have something that comes through the contact centre that's logged in terms of a concern or from a safeguarding perspective, if there's any kind of a worry or even if there's just an action that's been undertaken so that if you have access to that system, you can get a view of what might be happening in terms of opening and closing cases, in terms of any safeguarding concerns there might be.

Interviewer: Does it show? Does it write the diagnosis if the individual has Huntington’s, can you see that it's diagnosed?

Respondent: Yeah, yeah, yeah. Well, that would be part of the assessment process or the initial information that comes would be logged in terms of the basic information, who the person is, where they live, their date of birth, and if there's a diagnosis of anything, whatever that diagnosis might be.

What I was going to go on to say was, you were talking about a newly qualified social worker coming in, having to deal with something and thinking, “Oh, I’ll just do what I need to do and then pass it on,” sort of thing. We talk a lot, and I mean a lot, about the need for professional curiosity, the need to look at the bigger picture, the need to don't just take things at face value. When we're looking at anything, whether it's a clinical diagnosis or if we're actually looking at an assessment of what might be going on in somebody's home situation or their relationship, look at the bigger picture, see what else is going on, what kind of nuanced conversation might you be party to, any kind of nonverbals, anything like that. But I don't know. Again, that feels like we're chip, chip, chipping away and people nod and say, “Oh yes, yes, it's very important to look at the bigger picture,” and then they just look at what's right in front of them rather than just taking some time out to think, “Is this really what's happening or do I need to think about whether somebody's being exploited or whether they're being taken advantage of?” or whatever.

[0:53:25]

Interviewer: Or just don't know, like I have a lot of patients telling me the benefits were removed or packages of care were stopped because people like, “So, how are you doing?” And they're like, “I'm fine”.

Respondent: Yeah, yeah, exactly.

Interviewer: And then care being removed because the person said they were fine. So, but I guess, but they don't know, they're not fine like.

Respondent: I must have done hundreds, and I mean hundreds, of Disability Living Allowance assessments in years gone by. So, and that's been changed to PIP in this country. So, you used to get DLA, now you get PIP. And when you do a DLA or an Attendance Allowance form, you've got reams and reams and reams, like pages and pages of information that's cross referenced to previous questions. And if you do that, if you say, which we're all driven to appear as well as we possibly can, nobody wants to say, “Oh, everything's terrible and I'm having an awful time,” when you fill in a form, you say, “Yes, I can manage at night. Yes, I can get up and go to the loo,” that sort of thing. And because the questions are cross referenced, if there's any anomaly in the information that goes into a what's now a PIP application, it throws up a kind of flag in the system and that causes people to have their benefits withdrawn or to not be able to access them.

So, I have, as I say, done so many of those forms in the past where essentially it's like a counselling session because you have to sit with people and say to them, “Look, I know this really hard and I know that you want me to think that you can do all of these things, and I'm sure that when you're at your best, you can. But can we think about when you're at your worst?” And here I am now in 2024 and a lot of my work is about strength-based work and looking at the positives that we can generate with individuals and working in partnership. And there's quite a lot of anxiety about that I think from workers and from individuals because they think it's a cost cutting exercise and it absolutely isn't. It's about us working in a purposeful way with people to get the best for them and for them to be able to identify what they can do. And yet, as I say, I've spent years and years and years counselling people and saying, “But tell me how awful it is and how you can't manage these things”.

So, you're absolutely right. If people answer in the affirmative and say yes, yes, yes, I'm fine, yeah, they are going to lose access to money and they're going to lose access to services. And I think it’s like shark infested waters. You know, it's fraught with difficulty out there for people because it's so hard for them to navigate successfully to actually get the big prize of having a service which they should be entitled to anyway. They should be entitled to good care. They should be entitled to a seamless assessment that actually improves things and doesn't make things worse for them. And it feels, going back to my kind of political soapbox, it feels like we're in a worse position in 2024, in post-Brexit flipping UK with all of the constraints that we have and the money that seems to be going nowhere. The only comfort I can take, to be honest with you [Name 3], is that we don't live in [Location 16] where the local authority’s gone completely bankrupt and they've had to cut services right across the board. And even in this region we have a local authority not very far from us in [Location 17] and they've cut things back to such an extent they don't have access to libraries, they don't have a leisure centre anymore in [Location 17]. They've withdrawn funding from sporting organisations and they used to fund a world class stadium, which was called [Location 17] Stadium, and they've had to withdraw funding from that because the local authority don't have the funding to continue with the support that they had in [Location 17].

And that means, unfortunately, over the long-term, because we look politically at very short-term bursts of time, don't we? But over the long-term, you're going to have people who are affected by obesity, who are affected by ill health, who don't have access to learning, who can't borrow a book from a library, who can't go for a swim to ease their arthritis. And over time people are going to get –

(Overspeaking)

Interviewer: The inequality just, the inequalities are just, yeah.

[0:58:05]

Respondent: Absolutely. So, you know, I do count us fortunate in that we're in a local authority that seems to take a relatively sensible view and hasn't cut things across the board, but that's not easy. We've just had a round of budget discussions within [Location 1], like all of the local authorities, and I know it was really hard for those people who had to make those decisions. But touch wood, they've just put our council tax up, but they haven't got services, so that's something. But yeah, it’s a toughie.

Interviewer: Yeah, I mean, we have a saying in [Location 18], which is Portuguese, can always see the good in the bad, and you're basically being quite Portuguese with like it could be worse, you know? It could be worse.

(Laughter)

Respondent: Yeah. Well, yeah. Glass half full and all that. But it’s kind of, yeah, that's my strength-based focus, trying to think about the good in the bad, but there we go. Okay.

Interviewer: You had told me to keep to one hour and I'm already overstretching myself. So, I'll move to the most boring questions, but I must do them just to help me have an idea of my participants. Okay, so how old are you, [Name 1]?

[redacted]

Interviewer: Okay. Alright. So, is there anything that we haven't covered that you would like to let me know?

Respondent: No, I think that, as I said at the start, I was slightly anxious that I might not have the practice experience that you required. I'm sorry if I've prattled on about all that's wrong with the world, but it just it does feel like the more vulnerable people that we have contact with have a really hard time. And I can't stress enough, I believe that for a healthy society, you're only as good as the way that we look after people and I don't think our society is looking after the most vulnerable people in the best way that it can. I think resources are spread very thinly and what that means is the more vulnerable amongst us find it harder to survive in the shark infested waters that they have to deal with. I think people, not just people with Huntington’s, but I think people with Huntington’s and Parkinson's and motor neurone disease and MS should have a much better deal than they have. I think it's hard for them and yeah, we've got a duty of care and it worries me that people aren't getting the best deal that they should be getting really.

Interviewer: Thank you, [Name 1]. Well, I agree with you, surprisingly.

(Laughter)

Respondent: Well, yeah, we're singing from that same song sheet, that's for sure. I mean, yeah, but for as long as I can, I will continue chipping away as I have been doing for it feels like a very, very long time now. And you know, it's sometimes you just see little glimmers. There are some great, great relationships that develop amongst support groups and individuals who are involved in community groups. But I just think it’s hard for people to muster the energy for that kind of thing as well. And COVID and lockdown really had an impact on a lot of support networks that I think are still struggling to reestablish themselves and to encourage people to get involved with them. So, it’s not just hard to recruit staff within adult social care, it's hard to recruit volunteers for organisations and to encourage people to take part from that point of view. And here we are in our society, the view seems to be well, you know, you find a voluntary organisation to meet your needs and there aren’t so many voluntary organisations that can support themselves, never mind meet the needs of others. So, yeah.

Interviewer: I think we're only all looking a bit at our belly buttons. And as you're saying that like am I contributing? Am I doing my contribution to society? You know, to pull the good?

Respondent: Yeah.

Interviewer: Yeah, I think we're all, it's not just the systems that are isolated. I think individuals are as well. So, you know, I know the things we spoke are again, they are quite much broader than Huntington's, but it is, yeah, I mean it would be naïve to just speak of Huntington’s in its own little island. That's not going to take us anywhere. Yeah, just the way it is.

Respondent: And it is and I think, as I said before, I think when people are under pressure or under stress, they marginalise and push people further and further out and the more vulnerable you are, the harder it is to survive in the difficulties that that we currently face. So, yeah, as you say, we couldn't just speak about Huntington’s, it had to be about the wider kind of vulnerabilities that we see around us. But yeah, I think that’s where the key lies, is actually about people being nicer to one another and communicating a bit better and listening. It's interesting that there have been over the years a number of kind of soap operas and dramas and things that are focused on particular conditions. And that actually is quite useful because it does raise some awareness. It might just be on a very kind of micro level, but it actually gets people talking about, oh, you know, that is a difficult condition and I'd never thought about that.

[1:06:27]

So, yeah, it's communication is the key and information and knowledge is the key I think. But it's just how we get there really, so…

Interviewer: Yeah, yeah, and [Name 6] does a lot of work on compassionate communities. I don’t know if you're familiar with him. It’s [Name 6], Compassionate Communities, and it's a bit like, I don't know, I think a lot of people would think it like, oh, that's wishy washy. But that's actually it's true. Like again, you know, do we know who our neighbours are? Like if my neighbour downstairs drops dead, would I notice? Would we found him only six months? It's a bit like, yeah, are we pulling our weight into this?

Respondent: Absolutely, absolutely. And are we kind of doing the best that we can do as human beings? That’s the key question that we've got to ask ourselves, isn't it? And I suspect possibly not. There are lots of people out there who look after number one and they're not in the slightest bit interested in being curious. And as I say, I mean we do spend a lot of time with our staff talking about professional curiosity, about asking questions. I've just done a whole raft of safeguarding training with our housing and construction staff, which is if you see something that makes you feel uncomfortable, say something, don't just keep it to yourselves. Do something about it. You don't have to do a big thing. Just tell us about it.

Interviewer: Yeah. Pass the ball. Yeah.

Respondent: Yeah, absolutely, absolutely.

[redacted]

[End of Transcript]