[0:00:00]

Interviewer: Yeah, okay. So, I’m going to save that. And then I’ll complete it and send you a copy just so that you have it as well. Alright. Okay. So, can we start if you tell me a bit about your work, about your role?

Respondent: I work for the Huntington’s Disease Association, so I’m a specialist advisor. I cover [locations]. I’ve worked for the charity for [nearly 20] years, supporting families predominantly, liaising and linking in with professionals, education and just ensuring families are supported, in touch with the right professionals and getting the care they need, benefits advice and training for said professionals. Yeah, all sorts of things. I’m a Jack of all trades and expert of none. Don’t quote that. (laughs)

Interviewer: Alright. Okay. And is this a part-time job or is it full-time?

Respondent: It’s 30 hours, it depends what you classify as full time or part time.

Interviewer: 30 hours?

Respondent: Yeah, just marginally part time.

Interviewer: Okay. Alright. Do you know more or less how many people you have under your wing?

Respondent: Yeah, so my case files, there’s about 200.

Interviewer: 200, okay. And do you feel that it tends to be more than that number?

Respondent: No, no, it kind of bounces around between 150 and 200.

Interviewer: Okay. And you started, you said about [redacted] years ago, right? Did you have any prior training in Huntington’s disease?

Respondent: No. So, my background, I’d come from a social care background, so historically I worked with people with learning disabilities, managing care homes in the community and moved into community services, preventative services, supporting vulnerable people in the community, so that included young offenders, people with learning disabilities and generally frailer older people. So, I managed a variety of projects that, as said, did preventative stuff to keep people safe at home.

Interviewer: Okay. It sounds like you had a pretty good background to go into Huntington’s disease then. When you started at the charity, was there training provided or I mean it was some years ago. I’m not sure how much…

Respondent: It was very different to how we do things now, so I started the job and there was shadowing, so I followed around other advisors in the area, so I didn’t have [location 2] then, so I worked closely with [name 4], who had [location 2], and a lady called [name 5] who did [location 3], but there was no formal like we do now. We have a whole sort of array of, yes, sort of training and safeguarding and all those sorts of things, but there was nothing formal when I first started. No, it was very different.

Interviewer: Okay. When you say there was nothing formal when you started, is there something formal now?

Respondent: There is, yeah. There’s very much… I think there’s sort of a six-month probation period and there’s kind of a six-week induction that they do shadowing opportunities and we do various online training projects. Yeah, so it’s very organised now, unlike it was in the past.

[0:08:31]

Interviewer: Okay. And you’re the only advisor covering these counties?

Respondent: Yes.

Interviewer: Yeah, okay. So, when you’re off, what happens with the families?

Respondent: So, they have a number of options. They obviously can link in with either their own Social Services or their own clinical support with [name 6], who’s the specialist nurse that covers the areas. We do offer a TR(?) service, so if a family needs to get in touch with an advisor for advice from the charity then there is always somebody available sort of office hours, so they can ring in to either my number or to the head office number and somebody will pick up that call and be able to give them the advice or the suggestions they need, or just take a message for me to pick up on my return.

Interviewer: And when do you become involved in people’s care? What happens usually is that they ring the Huntington’s Disease Association or…?

Respondent: So, it varies from person to person, so some people get involved… sorry, the cat and the dog will get involved.

Interviewer: That’s alright. No, I have my puppy around there as well.

Respondent: Some people get involved because they’re at risk and have those conversations about the family member who’s affected and then they’re in touch with the charity. Some people come through from genetics because they’ve had a positive or a negative test result and need some support with that. Most people come through when things get complicated and their needs are changing and family need support about engaging with Social Services and clinical service and they’ll reach out to the charity because obviously we’re quite Googleable. And then we…

Interviewer: It’s a mouthful.

Respondent: We can signpost to the most appropriate services that they need.

Interviewer: Would the genetics, so I imagine the genetics team have your contact and they will link you?

Respondent: Yeah.

Interviewer: Okay. Do you still sit in the clinics at the hospital?

Respondent: No, no. So, obviously you were involved in the past. We were in a very small room with a lot of professionals staring at a patient, which I found very awkward, so we spoke to [name 6] and obviously things changed through Covid, so the arrangement is so [name 6]’s obviously in clinic, so if there’s something for me to do then she’ll alert the family to me and then I can follow up after clinic because we don’t all need to be sat in that room. I found it very intimidating and not a very pleasant experience so I really felt for the setup, and that’s not a criticism of the hospital or the team involved, it's just about rooms, isn’t it, and how that was managed. So, it’s, yeah, so [name 6] and Chris are involved in clinic and then they’ll link people in as appropriate after the appointment.

Interviewer: Okay. So, how do you see people? Are you still going to people’s houses if they want or is it mainly via phone and email?

Respondent: Whatever suits that family member, so we can do a lot more remotely now, obviously, as you’re aware. Since Covid we’ve realised that we can achieve quite a lot virtually and over the phone, so we’re encouraged to do that more because that’s a lot better use of our time and enable us to reach more people more efficiently, but for new families or if there’s a particular piece of work that needs to be done or if somebody’s communication isn’t quite as clear as it would be then we absolutely go and see people at home.

[0:12:31]

Interviewer: And is there a way, I mean I’m asking because I really don’t know, is there a way you organise your appointments when you have a new person referred to you? Is there a structure to organise the appointments or you just have a feel for what the person needs and discuss, or is there like a template to go through or…?

Respondent: Yes and no. So, there’s kind of a mental sort of checklist in my head as we meet new people, just ensuring all their clinical needs are met, liaising with clinic, speech and language therapists and those sorts of people, looking at benefits, ensuring people are applying for the right benefits. We have conversation about Power of Attorney and legal plans. We can link them in with the right people to be able to do those bits and pieces. And ensuring they’ve got emotional support, so linking in with branch and other families if that’s something they want. So, there is kind of a format, but it’s not written down anywhere, it’s just sort of going through what support that person needs and then ticking those boxes.

Interviewer: And that’s something you’ve… that mental checklist is something you’ve developed with your experience on the job?

Respondent: Yes.

Interviewer: Yeah, okay. Is that something that you exchange with other advisors, you know, younger advisors, for example?

Respondent: Yeah, I think we all come from different backgrounds, so obviously my strengths are my social care background and having that knowledge. Other people have other strengths and other backgrounds, but that format I’m sure everyone goes through the same sort of thing, that the right clinicians are involved, linking in with branch and signposting for benefits. So, some people don’t have a strength for benefits, so in a past life I was at a Citizens Advice, so I do have a strength for benefits and PIP forms and things, so I’m quite comfortable supporting people with that. So, you know, we all bring different skills and although there’s kind of a process that we all go through, we may do different things differently. Lots of words there.

Interviewer: Okay. So, you’ve mentioned linking with clinicians and that I imagine for the benefits you link in a lot with social workers, I imagine, as well?

Respondent: DWP, yeah. The Department of Work and Pensions, yes.

Interviewer: Alright. And you mentioned training in nursing homes, did you say something about…?

Respondent: Yeah.

Interviewer: Yeah, okay. So, the training in the nursing homes, how does that come up? Is it in nursing homes where people have Huntington’s patients admitted and they contact for training or…?

Respondent: It’s a bit of both. So, some nursing homes will reach out and ask us to get involved and meet with the resident and the staff and talk through what they’re finding particularly difficult. Some like the formal training face to face, but we currently have quite a substantial virtual educational package, so every month or two we will push that round to nursing home and other professionals that are working with families we know and giving them the opportunity to tap into what we’ve going on.

Interviewer: What’s part of that educational package, do you know?

[0:16:12]

Respondent: Various things, so our current one, we’ve got a PEG webinar coming up. We do an overview once a month. We’ve got a mental health day that [name 6]’s very kindly talking at for us. We have OTs. We have DVLA. We do different things, so it’s, yeah, different speakers, and some of them are family-orientated and some of them are aimed at professionals depending on what the subject is, so it’s a rolling sort of programme. We have an educational lead who will plan the next month’s events and that will be on our website.

Interviewer: Oh, sorry, I thought when you said it was an educational pack, I thought it was like some prerecorded like modules or something.

Respondent: We do offer that, so there is a virtual course that has been developed, so there are certain modules to it and, yeah, you kind of get a certificate at the end of it. Don’t know a massive amount about it because it’s very much in its infancy, but that is something that’s being developed with the management team and the education lead so that people can do a course, an online course that involves different elements and then they complete the course and obviously they can take that with them going forward.

Interviewer: So, I mean with the news that I read is that there’s issues with retaining care staff.

Respondent: Yeah.

Interviewer: So, do you think in the long-term care settings, like nursing homes, where potentially there’s a lot of rotation of staff, that the staff are kept trained, you know, that the rotations keep up… you know, the training keeps up with the rotation?

Respondent: It would be nice if it did but, you know, it’s a tricky one. The nature, as you know, of Huntington’s is it can be very complicated and people can present very differently, but whenever I go into a nursing home, if people are good at their job and patient and know to take their time, those are the skills they need to be able to communicate with somebody who’s symptomatic of Huntington’s. So, people are good at their job, they don’t need that niche, specialised knowledge. You know, it’s helpful and it kind of gives them some insight into some of the trickier elements that are associated with working with people with Huntington’s, but it’s just about being patient and just taking your time and all those sorts of things. So, you know, a good, skilled carer I always feel should be able to work well with most people.

Interviewer: Yeah, yeah, I agree as well. Okay. So, are you… I’m going to touch a bit on your perception of how people feel in the county about… I’m sure people give you feedback and how is that feedback? Are people happy with the care they’re receiving?

Respondent: I think historically, so before we had [name 7] involved, [name 7], we had nothing in the county and people were going to [location 4] for clinical care from [location 5] and [name 8] and her team there. So, when [name 7] came on board, that was a massive leap forward because he was very knowledgeable and very empathetic, which is what we hadn’t had previously in neurologists that had been involved with people’s care. And when [name 6] came on board, that took us to another level as well, and obviously with [name 7] we have ENROL and the research side of things. So, I think in recent years, people feel they’re getting a good service. I think the things that are letting families down are the lack of social care the lack of… the wait for speech and language therapists and those sorts of things. I think what we have is good, I think we need a lot more of it, and the demand for services and the response we get is poor, and that’s not a reflection on [name 7] and [name 6], because they are very responsive and do an excellent job. It’s everything else that the families need. And you look at other professionals that should be involved, the demand and the lack of qualified staff, you know, yeah, families are waiting a long time for the right input.

Interviewer: So, with social care, which you’re saying it’s not quite at the level people would like, what is it that would make it better? Is it being seen quicker or…?

[0:21:30]

Respondent: Being seen quicker, people having more understanding of Huntington’s. Yeah, just they do a lot of things over the phone, so I’ve got a particular chap whose situation is dire and Social Services and professionals keep phoning him and he keeps telling them he’s fine and they’re quite happy with that response, so I’m trying to flag him up as somebody who I’m concerned about and getting professionals actually across the threshold to see what I’m concerned about is proving to be very challenging.

Interviewer: And when you’re trying to chase this, is it you have to ring or contact Social Services as an organisation, or is it an individual? Is this like a…?

Respondent: No, it’s a call centre, so Social Services is a call centre, so you flag your concerns, you make your request and then it goes in a holding, waiting system, and then it gets triaged and they make phone calls rather than visits. That’s, yeah, that’s the way things are done now, whereas in the past I’d be able to get a named person and ask them to visit. They’d do that ten years ago, they don’t any more. Everything is much more remote and not individualised. You know, you kind of just get given (overspeaking).

Interviewer: (overspeaking).

Respondent: Yeah. You’re given to a team as opposed to a named individual.

Interviewer: Okay. So, do you think would it be better… I don’t know, I mean does it ever happen that people have a named social worker allocated or…?

Respondent: Yes, yeah. So, if people are deemed to need that level of input. I’ve got a couple of people who have a named social worker, but historically they do a piece of work and then they’re closed to Social Services, so then you go back into the holding system again if there’s another problem.

Interviewer: Oh, so they’re like discharged?

Respondent: Yeah.

Interviewer: Because they stopped having Huntington’s or…?

Respondent: Well, you know, if care’s needed, care goes in and then that box, you know, nobody has the capacity to hold a case long term. That’s not the way social workers or speech and language therapists or physios work. You know, they do a piece of work and then you’re re-referred in.

Interviewer: And then you can be allocated to a different person?

Respondent: Yes.

Interviewer: Yeah, okay. Okay. So, ideally, what would that… you know, if it worked well, what would it look like?

Respondent: Ideally, there’d be people that hold cases long term and, you know, [name 6] is very much instrumental in that that she can work with GPs and do that long-term work, but, as you know, there’s one of [name 6] and she covers a massive area and she’s part time and she does [redacted] dementia as well and she’s very instrumental in people’s clinical needs and picking up the phone to Social Services and those sorts of people, but she has her own limited capacity as well.

Interviewer: Okay. So, ideally we would have someone more, I guess, continuity, someone that could carry on with that family and that you could, on a named basis, get in touch with when something is flagging so that you don’t have to keep chasing a phone.

Respondent: Yeah.

[0:25:21]

Interviewer: Okay. Right. And then you mentioned the referrals to speech and language therapists, so is there a big delay in people, from being referred to being seen, or is it taking time to get referred even or…?

Respondent: The referrals go in, so I did a referral last summer and my chap got seen today, so that’s taken eight, nine months.

Interviewer: Okay. And you did the referral?

Respondent: Yes.

Interviewer: And then…

Respondent: I can’t refer straight into NHS clinical support, I have to ask the GP to do it or [name 6] does it.

Interviewer: Okay. So, when you have to link with the GP, is that better or worse than when you link with the specialist nurse?

Respondent: [name 6] is a lot more efficient and a lot more prompt at what she does, so, you know, being in a GP surgery, you don’t have a named GP any more, so again it goes to admin, so there are more opportunities for things to slip through the net if you’re going via a GP because there are various people who are going to be involved in that referral, so it will go to admin and it will go to the GP and then it will go back to admin for the referral to be made, whereas if I put a request to [name 6], [name 6] obviously does that herself.

Interviewer: And with the GP, if there’s no named GP, so if you say, “Well, Mr John needs to see a speech and language therapist because of this,” so what… I mean if the GP doesn’t know the individual even, what is he… does he add something to the letter? Does he see usually the person before he refers?

Respondent: No, no, they’ll just do the request for me on what I’ve asked for.

Interviewer: So, you said you referred a chap summer and it’s been six, seven months and he’s being seen now. Alright. So, yeah, okay. Is there something people are particularly happy with, just to get out of the negative bubble?

Respondent: Yes, yeah, so [name 6] and the clinic, again, for those families that have been round historically as long as I have, you know, there was a time when we didn’t have clinic. So, the work that [name 7] has done and definitely the work that [name 6] has done has improved the care the families are getting tenfold. And [name 6] is very responsive. People will leave a message and she will get back to you that day or the next day. There isn’t a lag. There isn’t an admin. There isn’t an answer… well, there is an answerphone message, but in the same way that you’d phone a GP surgery or Social Services, you know, you’re phoning [name 6] directly and she manages her own workload so she’s very responsive and families are very thankful for that, very grateful, and very grateful for her knowledge.

Interviewer: Okay, that’s good. So, expertise seems to be quite an important thing. Do you have people that go directly to the GP that are not able to reach the expert services? Or usually…

Respondent: Yes.

Interviewer: You have people that need to access but can’t?

[0:29:15]

Respondent: So, there will be families that won’t have had a genetic test but are clearly symptomatic or are beginning to show symptoms or there’s some mental health problems, so going via the GP and trying to access mental health services is a challenge because every service is stretched. But obviously to be involved in clinic and [name 6], you need to have a genetic test result to access their services.

Interviewer: Okay. And knowing that, are families still not wanting to do the test but getting treatment for whatever is bothering them?

Respondent: Yeah, some people don’t want to be tested. Some people, and you know this from your experience, that they have no insight, that they’re fine, you know. There are a number of people who present very challengingly, but their perception of how they’re living and how they’re coping is not what we’re all physically seeing around them. You know, they think they’re doing well, so getting that person to engage and be proactive in their care and their services is very challenging.

Interviewer: And does that fall on you as the advisor in these situations? I’m thinking…

Respondent: Yeah, if their family’s all they know, then yeah, I’m kind of that link into the GP. The gatekeeper of any clinical service is the GP, so I can encourage family members and work with the GP to engage with what that person needs, but that person needs to want to engage, and that’s where we get a lot of difficulties because they’re poorly, they don’t want to engage, but professionals like GPs and social workers don’t understand the complexities of Huntington’s enough that that person doesn’t have that insight, so they’re not making an informed decision about their needs.

Interviewer: So, in that situation, how does the GP link with you if the person is not diagnosed? I’m thinking of… I mean I’m not sure if you would know all the families, so I’m asking if a person goes to the GP and they have not done their predictive test, how would the GP find you?

Respondent: Google. GPs Google.

Interviewer: They would need to know the person has a history, a family history of Huntington’s and they would find you. Okay, so there’s nothing like other clinical, like other medical records in the surgery, I mean how does it even flag that the person has a history of Huntington’s or…?

Respondent: I wouldn’t know if that’s on a system or not. [name 6] would be the one to ask that question.

Interviewer: Okay. But you do get calls from… you do get contacted by the GPs to say, “Well, I have a person here, I haven’t tested, they’re struggling with whatever and I don’t really know Huntington’s disease, can you help?”

Respondent: Yeah, occasionally, yeah.

Interviewer: Okay. Alright. Okay. So, from what we’re discussing, it would help if social care was more accessible and then personalised and proactive in keeping, well, in contact with people. Do GPs, is it realistic to think of training the GPs and the social workers on Huntington’s disease or…?

Respondent: It’s something we’ve tried to target previously, but the nature of any statutory service is they’re very overstretched, they have very limited time and the turnover of staff, we’re never going to be able… you know, if that was part of some sort of training regime, we would never be able to keep on top of new people coming in and people leaving. And Huntington’s rare, isn’t it? If you look at a GP or a social worker and you think of the number of people they’re in contact with and the number of conditions they’re involved in, Huntington’s… a lot of my contact with the GP or a social worker, they will say, “This is the first person I’ve met with Huntington’s,” or, “This is the first time I’ve dealt with Huntington’s”. So, you know, it’s… going back to good carers and good GPs and good social workers, it’s just about being good at your job and just asking the right questions and having the right approach. I don’t… I’ll probably get shot down in flames, I don’t think people need to know the complexity of Huntington’s, they need to know where to ping people to. We need to have those experts to be able to signpost people onto. But I think the gatekeepers of social workers and GPs and those people just need to be able to assess an individual in front of them and look at what they need and make sure they can be pinged to the right people.

[0:35:08]

Interviewer: Okay, so it’s getting people into the right pipelines. Okay. So, in my study, what I’m trying to do is to think of what could help care be more integrated between health and social or public and private, and as you’re saying, quite a lot of people on my first part of the study on the survey said there aren’t, you know, social workers aren’t expert enough, GPs are not expert enough, so they want more expertise. Realistically, it’s not possible to make all social workers and all GPs experts, so I really appreciate your point of we can’t train them all and we can’t keep them all trained, so can we make access to the experts more (overspeaking)?

Respondent: It’s working collaboratively as well, isn’t it, you know, that we have [name 6], we have the charity, we have various other professionals that have worked with a number of people with Huntington’s so have built up their experience. And it’s just bringing those professionals together, you know. We can’t all know everything about everything. I wear a HD hat, but I don’t profess to know about swallowing assessments and capacity assessments, so I bow down to other people’s expertise. So, we’ve just got to work on a more joined-up way, which is where we were going with clinic and trying to involve ENROL and genetics and myself, you know, we were building a cohesive team, and it’s just trying to develop that sort of model and ensuring that you can draw on the right experts for the family to feel that the right people are involved.

Interviewer: That still leaves social care out thought, isn’t it?

Respondent: It does, yeah.

Interviewer: Yeah, okay. We haven’t quite cracked that one.

Respondent: No, and I think we’ll be fighting that battle for a long time. I think the powers that be have tried to join them together in some capacity, but it’s not been successful.

Interviewer: Do you… I mean I’m not sure if advisors meet, I don’t know, if there’s like an annual meeting of HDA advisors or something, but are there other counties where health and social work potentially are more joined up, that, you know…?

Respondent: I wouldn’t know the answer to that, so I can ask the question, but I’ve got the feeling the answer’s probably not cohesively. I think there might be little pockets where different projects have worked well, but I think they’d be very much in the minority.

Interviewer: Okay. Alright, yeah. As you were saying, it seems to work quite well in terms of health, because you and [name 6] and [name 7], you all know each other very well and known how to link up very well with each other. But yeah, social care still comes out as a very, yeah, silo area.

Respondent: It’s because it’s always changing, you know, and going back to me being around a long time, if I get a social worker I’ve worked with before, that doesn’t happen very often, but yeah, there is no one person in an office that you could say this is our point of contact for people with Huntington’s. That would be kind of the gold standard if social workers could, you know, if they had one person who’s in the team that would pick up all the HD families in the area, that would improve things because then they’d have that continuous knowledge and that continuity of care. Families are fed up of changing. You get carers in your door, you won’t see the same one for weeks, and the same with social worker and OTs and physios, people come and go and they’re constantly having to repeat themselves. But if we had a gold standard of where we’d like to be with social care, if each area, so obviously I’m in [location 6] and we’ve got [location 7] and we’ve got [location 1], if there was a named social worker that would pick up the Huntington’s families, that would give [name 7] and [name 6] somebody to feed into, somebody for me to link with and that would be a really cohesive, holistic way forward and support for the families and they could pick up the repeat referrals, you know. We don’t always need somebody opened long term to social care, but if they could go back to the same person then that would give the families the reassurance that that continuity is there.

[0:40:46]

Interviewer: Okay, yeah.

Respondent: So, if you could make that happen, that would be marvellous.

Interviewer: Yeah, no, I mean why not really? I know it’s quite simplistic, but in the hospital we have… there’s different specialties, so why is social work such a big umbrella. And I’m sure there’s some sort of… there must be some sort of… I need to speak to a social worker, that’s what I need to do. But there must be some sort as well, like categories within areas, but that’s not… people are not experiencing that, so something is failing for sure. Okay. So, this is my next hard question, which is let’s say we do get this and we have a named social worker and people… you know who to ring or who to email and even people are discharged at that point, they go back to the same individual and, “Oh, look, I haven’t seen you since,” but same person. How… what difference would that make in people’s lives in terms of, you know, what is the change? Is it like less anxiety or just a quicker referral?

Respondent: Yeah, I think if there was such a service, that we had a point of contact with Social Services that dealt with the families in that area, then obviously it would be quicker. There wouldn’t be this triage system where people are waiting eight weeks to see someone for their referral to be picked up from Social Services. There wouldn’t, yeah, the families would be reassured. They haven’t got to keep explaining themselves. That person would have the knowledge and the expertise of Huntington’s and also of that family’s circumstances. I think it would take away a lot of anxiety and stress for the families. They’d have that continuity which people with Huntington’s really need. And there would be a relationship with that person. That’s what [name 6] and I and [name 7] and the people in ENROL, that’s what we always bring is we have that continuity. The families know us and we know them and there’s just that sense of comfort in that relationship for all parties. It just makes it a lot easier for everyone.

Interviewer: And because this doesn’t exist and people can take a long time to be seen, and I imagine some situations are actually quite dire, as you say, and so what sort of consequences have you felt regarding this gap?

Respondent: I think situations deteriorate quickly, don’t they? You know, when we’re talking about family members who have got advanced Huntington’s and they’re not able to look after themselves and they haven’t got a family member who’s able to support them with their care or advocate on their behalf, my workload, as is [name 6]’s, deals with a bit area and lots of patients. We’re not seeing somebody every six weeks; we’re seeing somebody once a year, once every six months, and the situation can change in the time that [name 6] and I are involved. And an urgent situation that could be flagged up to Social Services for intervention, if their triage system is about eight weeks, those eight weeks can be quite critical for somebody’s skills, their independence, their personal care, their self-neglect, they’re malnourished, actually that period of time is too big, that actually an urgent situation can go from urgent to quite seriously dire in that period of time, so it’s leaving vulnerable people in some very unacceptable situations.

Interviewer: So, this is very focused on the person that lives with Huntington’s symptoms. Do you feel that carers are negatively impacted as well with this massive delay? Like if they really need… imagine someone, you don’t have to imagine because you’ve had plenty of situations, but if someone really needs to go into long-term care because their needs are really so complex that they can’t stay at home with whoever is taking care of them, does it take people to the extreme to really pushing their…?

[0:46:18]

Respondent: Yeah, so carers, carers are constantly fighting every professional and every battle on the front of the person they’re advocating for, so nothing comes easy. If they want respite or if they want access to a neurophysio or any of those things, there are gatekeepers and there are barriers. You know, nothing comes easy to a carer and, yeah, there’s a lot of carer stress and carer fatigue, which is exasperated because of the wait for anything, you know. In our area, the only person that is responsive is [name 6].

Interviewer: Okay. So, we should see an improvement if we were able to provide better access, quicker and better as well, we should see improvement in the carers’ outcomes as well. You mentioned their stress and their fatigue, okay. Do you struggle, I mean do people struggle to find a nursing home that accepts Huntington’s patients in [location 8] or not?

Respondent: It depends on the need of the individual, so we don’t have any specialist Huntington’s services in [location 8] or [location 2], but we have some very good, experienced nursing homes, and there is a neurological centre in [location 2] that deals with more complex individuals. But I think if people are presenting with quite psychotic and psychiatric symptoms then we very much struggle. We usually signpost out of area to more specialist services because the needs are actually quite complicated and managing them in generic nursing environments is often difficult and not successful.

Interviewer: So, where do people go then, sorry, when they’re more psychiatrically intense?

Respondent: So, we ping to places like [location 9] or [location 10], which his [location 11], or [location 12] for those that are very, very challenged, so there are various organisations or nursing homes that will specifically deal with the more complicated people with difficult manifestations.

Interviewer: And you sort of know… I imagine families will question because they may not know what to do or where to send people, and you know because you’ve been working for [redacted] years and you already know who to advise and not to. I know you sent me a list of care homes. These are based in your experience and the feedback you receive?

Respondent: Yes.

Interviewer: There’s no like audit or something? There’s no such thing that the HDA go to audit the places or…?

Respondent: We have an accreditation scheme, so if a care home wants to be accredited to the charity, there is a fee that comes with it and there is an audit and assessment and we have our own staff that will go and do those assessments and work with that care home and sure the staff are trained up and that they’re, yeah, they’re up to the standard that we perceive they need to be, and then that’s reviewed every year if they wish to stay on the accredited scheme.

Interviewer: Alright, okay. That’s good to know. Is that something like national?

Respondent: It is, yes.

Interviewer: Yeah, yeah, okay. I didn’t know that. Okay. So, do you think we need something to provide better joined-up care?

Respondent: Yeah.

Interviewer: Is that something that… if I would say, if I had the magic way, you think it would be necessary to try and apply something?

Respondent: Yeah. I think there’s always room for improvement and there’s always… I just think we need to work more joined up. You know, what would be lovely and I’m not sure if it’s realistic, but you look at other clinics that have multi-professionals in clinics, they have psychiatrists, they have physios, they have a really extensive team, so to emulate something like that for the families to have one stop to meet all their clinical needs would be awesome, you know, from an NHS perspective. If we could do something more joined up with Social Services, not just for my Huntington’s families, not that I’m biased towards them, but for all vulnerable people, you know. If there was some way going forward that they worked more joined up, then that would benefit all of society, wouldn’t it, that people leave and things change and everyone’s overworked and there’s no staff and there’s no budget and yes. We could all have a little daydream about what it could look like, but in reality it’s very much kind of the golden standard, isn’t it?

[0:52:18]

Interviewer: When you say a one… what’s the expression, one-stop shop? No? One…

Respondent: Yes, one-stop shop.

Interviewer: Yeah, is it one-stop shop? These exist in England?

Respondent: So, the bigger clinics, so if you look at [location 13] and [location 14] and those clinics, they’ve obviously got a lot more clinicians in their services, [location 1] compared to those sorts of set-ups is very small. But that’s, yeah, it’s just where we’re at. But it’s finding those professionals and making it a bit more joined up.

Interviewer: Okay. Thank you, [name 1]. I’m going to do a bit of generic questions now, just give you a bit of breathing space.

Respondent: That’s alright.

[redacted]

Interviewer: Okay. So, [name 1], is there anything that you would like to add to our chat that we haven’t covered?

Respondent: All sounds very interesting.

[0:54:12]

Interviewer: All very utopic.

Respondent: Yes. It’s just, yeah, you know, you’ve met the families, it would just be wonderful if it was all just easier for them, you know, but it is just the state of all statutory services at the moment, isn’t it? Everything’s at breaking point and that just, yeah, makes a difficult situation even more challenging, and it shouldn’t be. Our families are having a difficult enough time as it is and if they’re asking for help in any capacity, it shouldn’t be as difficult as it is.

Interviewer: My experience when something is at a breaking point, that being health or the government, it tends to have a crisis and then improve from the crisis, so let’s hope it’s an opportunity.

Respondent: Hopefully. But, you know, going backwards to my previous job and even in the first five or ten years of doing this role, people used to do preventative stuff. People didn’t used to have to get to crisis, they used to just have to say, “I’m getting to that point. Can I have respite? Can we have day care? Is there a medication?” And stuff would happen. People used to do preventative stuff. We didn’t have to wait for it to get to a breaking point and then react, and it worked better for the families at that point. Times have changed.

Interviewer: So, you feel that now, at the moment, it’s more like stuff needs to happen in order to have some action, is it?

Respondent: Yeah, no, everything has to, as you say, it has to reach crisis. Somebody has to set fire to their house or wave a knife around or something for people to react and get that intervention that they need, and it shouldn’t be like that. We shouldn’t let people get that distressed or that unwell or the carers to have to cope with that level of difficulty. What kind of world do we live in that we’re letting people suffer and struggle and put at risk?

Interviewer: Yeah, well, don’t get me wrong, earlier I meant like political, government crisis, not letting people, yeah, burn their houses.

Respondent: Yeah.

Interviewer: I mean, again, you know, I sort of try to keep up with English and Portuguese news, which is hard, but my reading is that we are getting into a crucial moment as well that make it or break it sort of situation.

Respondent: Definitely. We need something to change, and let’s hope it happens. Even if there is a political change or the current policies go, “Ooh, yes, actually we need to fund the NHS better and social care,” it’s going to take time, isn’t it? We haven’t got people training to be nurses and doctors and OTs. We haven’t got those professionals coming in to move through, but yes. Hopefully by the time I retire it will be different.

Interviewer: Yes. And you still are working for another 50 years, so it gives us time, because you’re young.

Respondent: Well, yes, I’m around for a while, but yeah. We need to hang on to [name 6] as well, or she needs to train up a little team before she chooses to retire.

[redacted]

[End of Transcript]