[0:00:00]

[redacted]

Interviewer: Great. Okay. So can we start, if you just tell me a bit about your current role please.

Respondent: Well right now, I’m a Consultant in Neuropsychiatry in [location 4]. I’m also an Honorary Professor of Neuropsychiatry at the University of [location 4] and I’m now part time. So I job share with another new consultant, and almost all…I work three days a week and I would say 99% of my work is Huntington’s related now, the three days a week, I do clinics, I conduct research and I do teaching, and almost all of it is Huntington’s Disease.

Interviewer: Okay. What’s the other 1%, if I may ask?

Respondent: Yeah, teaching on other things, some old legacy patients who I’ve kept on with other conditions.

Interviewer: Okay.

Respondent: But that’s it really.

Interviewer: And when did you start working with people with Huntington’s Disease?

[00:07:35]

Respondent: About 30 years ago. I think about [year]. [redacted]

Interviewer: In what capacity? Was that…?

Respondent: I was a trainee doctor. Well I was a qualified doctor, but I was training in psychiatry, so I attended a genetics clinic to do with Huntington’s Disease and started seeing patients, before they had predictive tests.

Interviewer: Okay, so it’s through the, yeah, predictive testing first. Okay. And then did you do any specific training on Huntington’s Disease, or was it, like, learning on the job?

Respondent: It was mainly learning on the job, but also within the psychiatry curriculum, so when you’re training to be a psychiatrist, some of it involves organic mental disorders, so I guess we trained that way, and I went to meetings of one kind or another where I just learnt things as I went. And you know, the [European HD organization] and other things. It taught me a lot of things over the years.

Interviewer: But you have a lot of, like, what to call it…charitable roles, I’m not quite sure. So yeah, although you’re part time in this clinical academic role, you…

Respondent: Oh yes, sorry, I also [roles redacted] That’s a charitable role, yeah. That’s an unpaid role. I’ve done that for about [less than 5] years now, I think.

Interviewer: And what’s your caseload more or less of patients in [location 4]?

Respondent: We have about 400 HD patients, but then there’s a slightly bigger community, because there’s family members who might be at risk, and that’s probably twice that number, another 800, who are family members who may or may not at risk or could be affected by what’s going on. So they’re not officially my caseload, but they sort of come under the caseload really.

Interviewer: So, like, it’s every person that enters the…for an appointment, is like a little cluster of people, amalgamated in one.

Respondent: I suppose the other way of looking at it is to say I’m on my fourth generation now.

Interviewer: Yeah. That’s an interesting way of putting it.

Respondent: So I started, one of my first patients was an elderly lady, who probably died a few years after I started, but then I looked after her son, who is now in his 60s, and then his daughter, who’s in her 30s, and then there’s another…so there’s a great-granddaughter now, who she’s at risk, but I don’t know her status.

Interviewer: Okay. And do you have a way to structure your appointments when you’re seeing someone, or how do you organise your appointments?

Respondent: Ah, that’s a good question, it depends. So I think the first thing I would say, if it’s a new patient appointment, we have a very standard structure for new patients, some of which is about Huntington’s Disease and some of which is about my institution generally and how they like new patients to be classified and qualified. So yes, we’ll just do the standard thing which doctors would do, which is take a history, examine the patient, including their mental state, do whatever investigations we need to do to confirm diagnosis or other comorbid conditions, and then have a management plan. But my institution obliges me to do risk assessments on patients as well, which I probably wouldn’t do normally. So all that’s done, it’s a standard format that’s on my electronic case records. But then follow ups, they don’t form a set pattern, it just depends on what the… So I guess by the time people come for follow up appointments, if they’re carrying the gene or they have symptoms, it’s very much a question of asking them how things are getting on really, and then just it from there. I don’t, within the clinical setting, I don’t tend to use rating scales, which I know some people do, because I don’t find them… I find they take up more time and they’re not that helpful. I’d rather just…go on?

[00:12:22]

Interviewer: I was going to ask you if rating scales, you know, like, motor rating scales or, like, cognitive?

Respondent: Well, any of them really, I don’t really use any of them. I mean, in research I use them all the time, but in clinical practice, I’ve never really found them very useful in this area.

Interviewer: So what do you find useful?

Respondent: Saying, “Hello, how are you?”

Interviewer: Open questions?

Respondent: I suppose the other thing would be, like, well, I already have a list of what the problems had been before, so I will sort of say, “Well, what about this problem, how’s that going?”

Interviewer: So you sort of, like, you look at patients’ notes before they come in, so that you have, like, a…?

Respondent: Yeah.

Interviewer: Okay. So you don’t have, like, a standard, you don’t…do you try to see people, like, every six months or is that just left open to people’s needs?

Respondent: It’s about every six months, but it could be more or less. I suppose there are certain things that I do ask patients every time, or I have to check that I’ve asked them. I always ask them about weight, and about swallowing, and about driving… I usually ask them, “What does your day look like? How is your day? What do you do? What is a day for you?” and of course, you might get a different thing from the patient as from the main carer, the spouse, usually. So I would say, “What does a day look like for you?” then the patient might give one version and the spouse might give another version, so you just have to explore that a bit.

Interviewer: Do you always see them together, or do you separate them sometimes?

Respondent: Sometimes separate them, but not straight away, I think probably get them both in to start with, but then it becomes obvious that you might need to separate them. And the way you do that can depend on the situation.

Interviewer: Yes, that’s my experience. There’s no standard way of doing it, which is…

Respondent: If you’ve got a medical student with you, you can say to the patient, “I really want to know how you’re walking, so I’m going to get the medical student to go and walk you around outside, just to see what your walking’s like, just for five minutes.”

Interviewer: Yeah.

Respondent: And then you can check with the spouse, you know, sometimes the spouses don’t want to say something in front of the patient, do they?

Interviewer: Yeah.

Respondent: Because they’re kind, and also they don’t want to get beaten up or shouted at on the way home.

[00:15:00]

Interviewer: Of course, yeah. And who is part of your team at [location 4]?

Respondent: Okay, we have a nice team actually. I guess the big, the main part would be occupational therapists, I find them… But then, so they form a big role, then I suppose clinic nursing and community nursing is a big role. Then speech therapy and dietetics, those are both big roles within clinic. So it’s usually doctors, nurses, OT, speech and language, dietician. We do have a physio, but not as an integral part of the team, so we have a separate physio we can refer people to who’s very good. I still haven’t quite worked out what physios can do, because quite commonly, physios will tell a patient what it is they need to do and the patient won’t do it. I mean, it’s not true in every case, but that’s quite common. So I’m still working out what the best role of a physio is in the clinic.

Interviewer: And with the community nurse, you mentioned the community nurse is part of your team/

Respondent: Mm, yes.

Interviewer: And she’s a community nurse because she’s a nurse that goes into the community…

Respondent: Correct.

Interviewer: Or is she a link in the community team?

Respondent: No, she’s in our team and she goes out into the community, quite often to see patients in care homes, but sometimes in their own homes. But she will also see patients who get admitted to hospital, which is quite common really, they’re always getting chest infections or breaking bones.

Interviewer: So tell me about that bit then, when they get admitted to hospitals, or where there’s…imagine there’s a fall or they choke, they get through A&E, and then what?

Respondent: Well, it’s funny, we’ve been discussing this recently, because I think we’ve identified that as one of the weak points in the pathway, so it’s very…I mean, the thing we were talking about this morning is that somebody in the middle to late stages might, I don’t know, get a chest infection or fall over and break a bone, get into A&E and the first thing somebody will say is, “They need a speech therapy swallow assessment.” So they have a swallow assessment, and the local speech and language will say, “It’s too risky, they’re nil by mouth.” And then they won’t have a second plan beyond that. So the patient ends up just not eating and drinking anything.

Interviewer: Does it show on the record when they come through A&E that they’re diagnosed with Huntington’s, or…

Respondent: It might not. It might not. You’d hope that information got through, but I think even if it gets through, it doesn’t always…and even if that information is available, it doesn’t always register with people enough for them to do something useful. But that’s why our current discussion is whether to have patient passports, because it doesn’t really need to be a passport now, it could just be a QR code, you know, kept on a bracelet or a necklace, so you could just open it, scan the QR code and then you’d have all the useful information right there. So I’ve just emailed the HAD today going, “Are there any examples of that in the UK for Huntington’s, and could we steal them please?”

Interviewer: Yeah.

Respondent: I think it’s one of the areas that we identified as being a weak spot, and that’s a potential way of improving it, I think.

Interviewer: I like that idea. I think it’s usually, I mean, I wonder how people are allergic to penicillin receive penicillin these days, for example.

[00:19:17]

Respondent: Yeah, you’d hope not many, would you? In the old days…

Interviewer: I would hope not, but whatever, you know, there’s a way of identifying it, isn’t it, and at least when I was at hospital, it would just, like, scream at me from the screen that the person was allergic.

Respondent: In the olden days, when we had paper notes, that was often a thing that you’d see written in big marker pen on the front of the paper notes, on the cardboard front, above the patient’s name, it said, “ALLERGIC TO PENICILLIN” across it.

Interviewer: Yeah.

Respondent: I remember that. I guess that’s the limit within electronic notes. Within mental health it’s not so easy to see, but maybe in acute medicine it’s a bit easier.

Interviewer: Okay. Well, I don’t think it’s that easier, because I’ve had patients coming into A&E, diagnosed already with Huntington’s and getting admitted to wards and then diagnosed with Parkinson’s.

Respondent: Oh really?

Interviewer: Yeah, so…

Respondent: That’s not good.

Interviewer: No, that’s not great! Okay. So the passports would be an ideal way of identifying it, of course, as you’re saying, even if they read it, it doesn’t mean that it clicks, but would they know that the patient falls under your team? Or that you’re the expert team?

Respondent: They may or they may not. But if you had a passport, they could. I think it would be nice on a MedicAlert bracelet or something like that. So you’d just have a little click here and then it would just take you to all the information. And then the first bit, you could say, “This patient has Huntington’s Disease, here’s their lasting power of attorney, they’re under our team, here are their following wishes and feelings.”

Interviewer: Yeah, yeah.

Respondent: As a basic. Oh, and, “They’re on these medications.”

Interviewer: Yeah, like a little summary.

Respondent: And then, “Here’s some useful tips for managing people with Huntington’s generally.”

Interviewer: Yeah. “Scan this QR code to know what to do with a patient.”

Respondent: Basically, yes. You could get it tattooed on their…maybe that’s too much, that’s too intrusive.

Interviewer: I’m not sure if that’s going to go through.

Respondent: Yeah, a microchip…

Interviewer: Well, as people’s skin wrinkles, there may be some difficulties.

Respondent: Ah, yeah.

Interviewer: Okay, so that’s one thing that you’ve identified as an issue. Which other teams or institutions do you work with in terms of managing people with Huntington’s Disease?

[00:22:10]

Respondent: Well, that’s changed over the years. I suppose community neurorehabilitation teams, I’ve consistently worked with them over many years. Community mental heath teams, particularly for people with more florid mental illness in association with their Huntington’s Disease. But from a historical point of view, in the UK anyway, I don’t know how it was and is in other places, that people with advanced Huntington’s Disease almost all came under psychiatry, this is when I first started in the 90s and 80s. Almost everyone with Huntington’s came under psychiatry, after a while anyway. And many of them were permanently resident in asylums, and those were closed down in the 90s, earlier in some other countries, but in the UK, they were closed in the 90s. And actually, when they closed, those patients sort of got excluded from mental healthcare, largely, so that’s why we saw what I call the rise of the private asylums, which is what’s happened in this country, they haven’t been the big Victorian institutions, but small companies have set up inpatient care for people with Huntington’s all round the country, usually in the countryside. I guess that’s probably true in [location 5] as it is in…and in [location 1].

Interviewer: Yeah, the same.

Respondent: I call them the new private asylums, but they didn’t like to be called that at all.

Interviewer: I guess there’s a negative connotation to the word ‘asylum’. But they’re basically doing the same, privately.

Respondent: But privately. But asylum could be a good thing.

Interviewer: It’s a matter of, like, why do they see it negatively, what is it that they see negative about it?

Respondent: I suppose, I mean, there are some negative things, aren’t there, but also, they were brought up on Erving Goffman’s book, *Asylums*. Do you know that book?

Interviewer: No.

Respondent: It was written in the 70s, late 60s, early 70s. It was called *Asylums,* and it was basically a sociological critique of asylums, to the extent.

Interviewer: Of the horrors?

Respondent: Of the horrors of asylums, which they were, you know, but at the same time, it also, when the asylums were closed, we lost something too, that wasn’t reprovided in many countries.

Interviewer: You don’t feel that the current, what we have now is a substitution?

Respondent: No, because I suppose for all the downsides of asylums, at least they were accepted within psychiatric systems, and now since the asylums closed, there’s been a move to say, “This isn’t mental health at all.” So if you have a mental illness that’s caused by a known physical thing, many psychiatric services around the world will now exclude you. And so we’ve gone from having something that was mixed asylums, good and bad, to basically outright exclusion. Which I think is probably, on balance, worse.

Interviewer: So where do people go if they need admission to a long-term care setting?

Respondent: So what happens there is they’re at home to start with, things get worse and then everybody says it’s not them, so that keeps going for quite a long time. So the patient will probably be at home and at risk for much longer than a person with another sort of mental illness, and then there’ll be a massive crisis, and then there’ll be a request to a local mental health service, who will probably refuse it, and then that will probably get stuck in a big argument for a month or two, and the in the end, possibly a bed will be found for the patient in one of the private asylums, you know, I don’t know… It’s happened to one of my patients recently, 100 miles away from their home. He’s okay, his mum’s not happy.

[00:26:46]

Interviewer: Yeah, of course, it’s much harder for the people, relatives to visit and…

Respondent: I would say the standard of care is probably slightly better in most of those places than it was in the old asylums, but not massively better.

Interviewer: Are people trained to manage patients with Huntington’s?

Respondent: I mean, yes-ish. It depends, it’s quite variable. Some care homes, you know, they really specialise in Huntington’s and they do really well. They manage really well and they’re okay. But other ones, you probably know, they have a sort of low pay, low skill, high turnover workforce, and so they work 12 hour shifts on and off, so you never have any handover. And so loads of things get missed.

Interviewer: Your community nurse, you mentioned she goes to the nursing homes as well, does she, I mean, how does she link with them, does it work okay like that?

Respondent: It does, there’s quite a lot of conflict though. Because sometimes you can go to a nursing home and it’s clearly below standard and then you might have to get involved in safeguarding alerts and explaining why it’s below standard, and that’s quite hard work.

Interviewer: Then she reports to whom, the CQC or…?

Respondent: Yeah.

Interviewer: When there’s safeguarding concerns?

Respondent: Yeah. That happens.

Interviewer: Okay.

Respondent: So I guess…that’s a tough question, because the business model of care homes and the companies that operate care homes is pretty sort of…they usually overstretch themselves financially through private equity, that’s common, and want to develop quickly, so that means cutting costs at all possible times. But of course, it’s not like your mobile phone, if it wasn’t quite right, you could just switch it. Because the patients are pretty disempowered really, so what that means is that those business plans will almost by definition, continue to exploit and exploit the patients by cutting costs, and that’s what we see, I think. And there’s so little pushback, which is one of the reasons in the Huntington’s Association we try to have a bit of pushback, which is that we want nursing homes to be accredited by the Huntington’s Association, which means they have to reach a certain standard before we’ll say it’s okay for them to have HD patients. That’s a new experiment. It’s partly worked a bit with head injury, because Headway had a similar scheme.

Interviewer: Who…so the Huntington’s Association has these, like, criteria, who reviews the institutions with these criteria?

Respondent: The Association, but the care home companies have to be willing to pay for that.

Interviewer: Okay.

Respondent: So we ask them to pay to be part of the scheme, we use that to employ people, usually quite skilled people, to go and look at care homes and say whether they meet the standard or not. It’s a relatively new scheme.

[00:30:34]

Interviewer: Do you have many that have been accredited?

Respondent: I think…I’m going to say about four so far and about another seven or eight in the pipeline. It got…we started it just before the pandemic and of course, with the pandemic we couldn’t do it at all. So we’re just really back into doing it again.

Interviewer: That’s England and Wales?

Respondent: Yes. So it’s an interesting experiment. I think it might shift the dial a little bit but I don’t think, it’s not going to change the fundamental problem.

Interviewer: Well, is this once the institution is accredited, like, would you go review it, their status?

Respondent: Yeah.

Interviewer: You’ll review it.

Respondent: It’s quite intensive really to do that, but if the care homes are willing to pay for it, which they might, then hopefully we can make that work.

Interviewer: Yeah, its just…I guess to convince them of the benefit, because what probably can happen is that there aren’t many nursing homes to accept Huntington’s Disease patients, and so they’ll be, like, Well, we can get patients either way, why would we pay?”

Respondent: That’s true, and it might be that, you know, it’s worth… What the effect that that might have is that you’re getting a relatively small number of cases that are more highly skilled and more dedicated to HD, which might, probably on balance, be good.

Interviewer: Yes, but also more dispersed through the country, which means patients are even getting further potentially.

Respondent: That’s also possible.

Interviewer: You need to start somewhere, and I’m not, you know…

Respondent: Not, but you’re right thought, you’re right. We have to wait and see, because sometimes you can’t always predict how these things are going to, yeah, because people will try and game the system, won’t they, so it will be interesting to see how that plays out in the next few years. But I guess what we’re in the position of trying something to see if it works. Because beyond that, I’m not sure what else we can do.

Interviewer: Well, yeah, sometimes I think it’s, as you say, there’s a lot of long-term settings with poor standards, and it’s how do we raise the standards and keep them at that level.

Respondent: It’s not in the interest of their business to do that. And the patients aren’t particularly empowered to change their provider.

Interviewer: Yeah, yes, of course, they’re vulnerable, so it’s easy.

Respondent: Yeah, and you know, it’s really hard, even if you were quite an empowered person, it’s quite hard to say, “I don’t like this care home, I’d like to change my provider to one down the road.” Because that’s usually what keeps businesses honest, isn’t it, and when that doesn’t happen, then the system will still operate to extract more capital out of it, which, it’s really good at that.

Interviewer: Okay. Let’s talk a bit about social care, if you’re okay with it?

Respondent: Yeah.

[00:33:58]

Interviewer: So on the survey, on the national survey that I did, it’s not looking good, but I want to know your experiences in terms of involving social care, if you have, I don’t know, is there a social care… You did mention, but is there a social care worker that links more with your expert team?

Respondent: No, there isn’t. I wish there was. There is a service in [location 6] and I grew up, it was a sort of mature service when I was setting up my service, so I used to go and talk to them. That was basically run by a doctor and a social worker, which seemed to me like a really good service model. So they have a social worker, a full time social worker, front and central for a Huntington’s team. Which I thought was awesome.

Interviewer: Commissioned by the same…?

Respondent: Yeah, I don’t know how it got to be, how it happened. There were different things, there weren’t commissioners in those days, it was something else, but yeah, effectively it was commissioned. So the service is run by a doctor, oh, a doctor, a genetic counsellor and a social worker were the key people in the middle of the service. And particularly the social worker it worked incredibly well. Because a lot of these patients have very, very complex social care needs, so I suppose we’re… Yeah, I haven’t got a good report for social services, not for individuals, because some individuals are amazing, but the system is really rigged against them because they’re so stretched now. And so I guess the first thing to say is the continuity is bad, because I mean, probably loads of people will tell you this, a social worker will pick up a case but their management will say, “You can’t hang on to that, you’ve got to take the case, do something, discharge the patient, refer back if they need something.” And of course, that doesn’t work for our people, because they will need a constant stream of things over many years, and they want one person who knows them really well, how they can trust and all that. So yeah, I would say right now, so the social fabric is poor, so not just social work, but social care generally, there's not much money, we know that, and so those safety nets are poor at the moment, and that tends to fall back on clinical teams, doesn’t it? Accident and emergency units.

I suppose that’s one side, and one of the other things that comes out of that, which is…its’ sort of weird convergence of different factors, is social services assessment, particularly of self-neglecting people, who would reject the patient because on the grounds of autonomy. So they’ve went to the patient, the patient says, “I’m fine,” “Do you want some social help?” “No, I don’t,” “Okay, that’s fine.” “The patient chose not to have help.” And I suppose you could argue it from different sides that, you know, part of it’s driven by the, I guess, sociology culture of autonomy being the principle ethical thing, which I’ve got some sympathy with, but also driven by a need to cut costs. And so…and also managing ridiculously difficult workloads. So it’s almost like two conflicting values came together, to suggest the same thing, which is rejecting the patient.

Interviewer: It’s just easier to, well, it’s made to drop the ball, I guess.

Respondent: Well, yes, the system is designed to drop the ball, but for two very conflicting reasons, and it’s sort of interesting, because that mirrors, in some ways, the asylum closures, I think, in that they were the same two sorts of factors that came together to lead to the asylums closing; on the one fact there’s a sort of left leaning sociological reasons, about institutions and personal autonomy, and then on the other side, there’s a sort of much more right leaning libertarian, personal responsibility, small state and cheap option, and those things converging together to exclude patients from services, which is sort of a very interesting social and political phenomenon.

Interviewer: Well, people want to be cared in the community, in their own homes, but with conditions, with…well, certain things need to be in place, they don’t want to be at home just for the heck of it. So the money that’s being spared from the asylums…

Respondent: Where did it go?

[00:39:07]

Interviewer: Yeah, well…

Respondent: Is it in the US? Where did it go? Because I think the US is an example of one of the…of a country probably where asylum closure went really quick, really early, and community provision was particularly poor afterwards, so that was…

Interviewer: It’s such a big extension of country as well…

Respondent: So I guess, so one of the…we think there’s a lot in self-neglecting patients, who are clearly at risk and in terrible trouble, but because when the social services come round, and sometimes mental health teams as well, and say, “How are you doing?” and they go, “I’m fine.” And then they writ back saying, “Patient has full capacity and has declined the service, goodbye.” And that doesn’t seem right to me, that seems like a dereliction of duty, and duty of care, which is…you can see the patient isn’t fine, they might think they’re fine, but they could be dead tomorrow because they don’t know how to cross a road or how to make themselves any food, or clean their own toilet or… And they go, “Well, they just said it’s fine.” That’s not enough, that’s not a subtle enough argument. Sometimes when somebody says they’re fine, you’ve got to be able to say, “Actually, no, you’re not.” I don’t know.

Interviewer: So do you have then family, like, carers ringing you to say, “She discharged him!”

Respondent: All the time, yeah, all the time.

Interviewer: And then do you even…I mean, can you even go back to them, you don’t even know who as there, do you?

Respondent: Oh yeah, you can and you can say, I mean, in that sort of situation, you end up having a polite but firm discussion with social services or mental health team, when you say, “Did you do a capacity assessment on their ability to understand their care needs?” and they say, “Yes, we did,” and you say, “Can you share that with us so we can have a look at it?” And then it probably turns out that they haven’t really done it that well, and then they share it with you or they play for time a bit, and then you realise that they haven’t really done their work properly, and actually, the patient had no capacity to decide what their care needs were, it was just, like, “They said they didn’t want a service, so that’s enough.” So I guess that takes time and energy to go back to those people and say, “No, I don’t think that’s right, can you have a look at capacity assessment? We’ll come out and do a capacity assessment with you, if you like.”

Interviewer: What do you think would help in this case then? I mean, I know they’re stretched and, you know, they basically want someone to say…it’s almost like they’ll take the first excuse to discharge because they’re spread too thin. But you’re spending a lot of time, you know, then having to go back and diplomatically challenge the decision.

Respondent: That’s the way. It’s always… I suppose in the absence of a change in policy, I don’t know whether there’s anything else that can be done apart from that. And I guess usually policy gets changed because something bloody awful happens. So probably someone will die in squalor and then it will be in the papers and everybody will say, “Something has to be done,” and there’ll be an investigation and then there will be, like, “[name] Law,” or something which says everybody has to have a proper capacity assessment in the following ways… You know, it probably won’t happen unless something awful happens, I would imagine, in a sort of Baby P equivalent or something. And then people say, “Baby P must never happen again…” and that means all sorts of things, not all of which are great, but…

Interviewer: That’s the way I see a lot of things happening in Huntington’s Disease, is that a really bad thing needs to happen and then there’s a plan.

[00:43:13]

Respondent: Yeah, and maybe the plan will stick and maybe it won’t, we’ll see. So I guess that’s where the patient organisations need to get involved too, on the policy level, because there needs to be policy, it’s not acceptable for people to say a person said, “It’s okay, I don’t want anything,” and everybody just to say, “That’s fine, they said they didn’t want anything, so we won’t do anything.”

Interviewer: Yeah.

Respondent: It has to be more nuanced than that.

Interviewer: Okay. They wouldn’t do that with, you know, people that are depressed that can say, “No, I’m fine.” They wouldn’t….

Respondent: YOu wouldn’t think so, would you? No, I don’t know why it’s…or maybe they would, I don’t know. Its’ a long time since I’ve looked after pure depression, so I wouldn’t like to say for sure.

Interviewer: Yeah. Well, yeah, god knows, yeah, maybe. I was under the impression that they wouldn’t, but… Okay. I know it’s nearly time.

Respondent: I’m good, we can revisit some of this if you want.

Interviewer: Well, you know, it’s a complex topic because there’s space for improvement at many levels, but…

Respondent: I suppose it’s identifying the really important levels maybe, what’s the priority levels? I don’t know, I’m not quite sure what your question is, so…

Interviewer: Yeah, so my question is about how to improve joined up, you know, integrated care between the different providers, and I know from the survey, the bigger gaps, so that’s what I will try to turn the model towards in terms of being realistic, because you know, I’m not going to fix social care, you know, as a PhD student, that’s for sure, but I can see… It’s been interesting to have a discussion with different stakeholders and understand their own perspective on what could change to make it better. I do want to…

Respondent: I’ve got nothing I would change, because there’s another factor, I think, relatively specific to Huntington’s Disease, and that’s the mental/physical divide. I think that’s, you know, saying…having a system where things are divided into neurological illness and psychiatric illnesses, is itself problematic in this area. And it leads to patients being neglected in the middle of that. I think particularly that’s happened, well, because neurologists aren’t trained to deal with, or not trained or inclined to deal with changes in behaviour and mental state, and many general psychiatrists now are not inclined to see patients who’ve got organic mental disorders, so mental disorders caused by known brain pathology. And that came up very specifically in the Westminster Hall debate which happened last year, the Hilary Benn address, when he said, “People with mental disorders should have the same rights to psychiatric care,” in his words, “Regardless of cause.” And I suppose that gets to the nub of the debate, if you have a psychiatric disorder that’s caused by a known neurological illness, that’s now become an excuse for mental health services not to engage with them. So you have a psychiatric disorder that’s caused by something that we don’t know or understand, then they will engage with that, but if it’s caused by something that we do understand, like the Huntington’s gene, then a lot of psychiatric services in the country will use that as a reason to exclude. Sometimes through hearsay and sometimes through written policy.

Interviewer: I’ve had some appointments where we discussed that the Mental Health Act was actually an issue.

Respondent: I don’t think it is. Well, it might be its application is, but its wording definitely isn’t. So if the Mental Health Act is used appropriately, then you could absolutely use it for people with Huntington’s Disease who have mental disorder. So I think the wording of the Act is fine, it might…

[00:47:39]

Interviewer: The interpretation.

Respondent: Well, no, it’s not…I would say I don’t know a single court judgment that would support the interpretation that organic mental disorders are not mental disorders. I’ve never seen that ruling in any course in the world. It would be interesting to know there had been a ruling of that, I would be very shocked. So I would say the law and the judicial interpretation of the law is all fine, I would say it’s the professionals that have changed culture, again, to exclude people really.

Interviewer: And do you think that’s because of…like, finances being stretched?

Respondent: We might have to have another appointment…that’s a very long story. It’s a long and complicated story. Oh gosh…and that goes right back, yeah, I think we would probably need at least an hour.

Interviewer: An hour for that.

Respondent: My version of that story.

Interviewer: Okay.

Respondent: A good way of looking at it, if you want to get a short version of that, there’s a fabulous book called *The Best Minds* by Jonathan Rosen, it’s not about Huntington’s Disease, but it’s about the political forces that led to the current state of affairs.

Interviewer: Okay, I’ll have a look.

[redacted]

Interviewer: Yeah, so it’s my last question and I have just, like, boring questions that I need to ask, just quick ones. If there was something in place that improves co-ordination, you know, that services would work seamlessly, which is a word that I keep on reading and god knows what that looks like in practice. What do you think the change would be at person level? So for the patients and the families, what difference would they feel in terms of, like, outcomes?

Respondent: Well, I guess, what would that look like? That would look like one particular team within the Health Service taking holistic responsibility for patients, and not having to shuffle between lots of different teams, and being able to manage mental disorder or mental change, as much as physical disorder and physical change. So they only had to see one team for everything. And the lines of accountability within those teams were clear. To me, that would be a beautiful situation. Then I guess the next argument – who does that? I would say it would have to either be, in the UK anyway, that would either have to be a psychologically-informed community neurorehab team, or a physically informed community mental health team. I think that, in the ideal world, with backup from a super-specialist service like ours.

Interviewer: Yeah, because I mean, you can’t have this level of expertise in every 30 miles, yeah.

Respondent: Yeah, that’s what I think, probably, like a well…community neurorehab or community mental health team, because I think community-based services are the best for chronic disease management, but obviously you need inpatient beds too, but you can manage a lot in the community with, you know, good care co-ordination. And community neurorehab teams or community mental health teams, they’ve got the mechanism to do that, and some do it a bit. But most of them, when they hear we’re involved, they just don’t want…That’s the problem, sometimes super-specialist teams make things worse rather than better. They just deskill everything around them.

[00:52:20]

Interviewer: Is it to pass on the hot potato?

Respondent: And also, somebody explained this to me in terms of the army, so in the army, they introduced a new group of people who were called the specialist tree climbers, and then whenever they got to a tree, they were, like, “Oh, we don’t know how to do this, call the specialist tree climbers,” so everybody just got deskilled, the generalists, when they knew the specialists were around, they all just lost confidence or lost something, and so just gave it all to the specialists. And probably, yeah, with the benefit of hindsight, I don’t know whether that’s always a good thing. Sometimes a well-informed generalist with backup from the specialists is a better manoeuvre, otherwise the generalists, just, they have an excuse not to do it anymore and get really deskilled, which is what’s happened.

Interviewer: Okay.

Respondent: So we’ve been the architects of our own downfall.

Interviewer: Yeah, it’s about…you’re talking about deskilling, it’s a bit like how do we make them feel empowered, with what you’re saying about having it as a backup, instead of feeling like they’re lacking confidence and therefore it’s, like, “Okay, you deal with this, this is your area, you deal with it.”

Respondent: I would say there’s been massive changes to the nursing curriculum, the mental health nursing curriculum, in that most mental health nursing curriculums in the UK don’t mention the word ‘brain’. Or don’t look at brain disorders.

Interviewer: It’s physical, it’s organic.

Respondent: “It’s not us, we don’t do that.” Which would be unthinkable 30 years ago. So that’s regression, I think.

Interviewer: It’s regression, yeah.

Respondent: We’ve gone back in those terms. It’s easy to look back to the old days and say everything was fine then, clearly it wasn’t, but we had…it was a much more RGN/RMN, which was perfect for this area. But I understand that might be coming back a bit. So dual training, RGN/RMN.

Interviewer: What’s that?

Respondent: So you’re trained as a general nurse and a mental health nurse. So you hold both registrations.

Interviewer: Well, that’s what I am, I mean, yeah, I don’t know the acronyms because we don’t have them like that in Portugal, but we have…yeah, we do adult, paediatrics, mental, physical, we’re nurses. Then you’re specialised into something, but as a degree training, you do all.

Respondent: That’s not the case in the UK.

Interviewer: It’s a four year degree course we have in here, for…

Respondent: We’ve lost that in the UK. So you literally go and train as a mental health nurse or psychiatric nurse, whatever you call it, you’ll never see a picture of a brain in the whole of your training. You’re frowning.

[00:55:24]

Interviewer: No, I’m frowning because I think, I agree, I think it’s a gap, because you’re already compartmentalising so early in professionals’…yeah, training, that it’s, and then they develop this mindset, which I think it’s harmful.

Respondent: I mean, it’s not surprising when a patient turns up on the ward, on an acute psychiatric ward, that all the RMNs will say, “Oh, this is not us, we don’t know anything about this, we were never trained about it, you know, we don’t want it because we don’t understand it.” So I don’t blame people for that, well, I blame the system for that really. I can understand individuals might do that. But…

Interviewer: Okay. How old are you?

[redacted]

Interviewer: Yeah, okay. So is there anything that you’d like to tell me that we haven’t covered today, for the last five minutes?

Respondent: Well, I would like to tell you the history of the series of errors and lost opportunities that was the closure of the asylums and the reprovision of community care and why that all happened and why it’s so relevant today, all over the world, but…you know, I wouldn’t say particularly in the UK, but definitely in the UK, and yeah, I would really like to tell that story to you but I can’t tell it you in four minutes.

Interviewer: No, but I’m certainly happy if you’re happy, you know, to book another date.

Respondent: How did patients with neuropsychiatric disorders get systematic excluded from mental health services, to the extent that nobody ever thought they were ever in them in the first place, even though when I first started, that would have been unthinkable. So you’ve had a group of people that have been systematically excluded from mainstream mental health services over 30 years, and I personally think it’s a scandal that that’s happened. And it’s not just in the UK, it’s happened in other places too. I suppose that’s important, isn’t it, for your…

[00:58:21]

Interviewer: Yeah, would you be happy if I scheduled another date?

Respondent: Yes, of course.

[redacted]

Respondent: It happened all over the world. And I would say, my last thing is the main reason, well, there are lots of factors, but factor number one to trigger all that off was John F Kennedy’s sister.

Interviewer: Alright, I’ll have to look that up.

Respondent: Rosemary Kennedy. Because JFK’s sister, Rosemary, had some sort of learning disability, she was institutionalised for many years, and during that period, she also had a lobotomy because that was the time when that was happening a lot, Freeman and Watts and all that. And (inaudible 01:01:16) of course, who originated it all. And because the Kennedy family were so guilty about that, then the last piece of major legislation that JFK signed before he was shot was the Mental Health Community Care Act, which is the first domino in all the dominos that fell round the world for the closing of the asylums.

[redacted]

[End of Transcript]