

An Exploration of Staff's Support with Adults with Autism in Occupational Engagement in their Daily Lives



Submitted to the Discipline of Occupational Therapy, University of
Dublin, Trinity College, in total fulfilment of the requirements for the
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Table of Contents

Appendix D: Letter of Invitation to Participate, Letter of Interest to Participate, Participant Information Leaflet and Consent Form.....	5
Letter of Invitation to Participate	6
Letter of Interest to Participate	7
Participant Information Leaflet.....	8
Consent Form	11
Appendix E: Participant Stories	13
Participant One	14
Participant Two	17
Participant Three	19
Participant Four	22
Participant Five	25
Participant Six	28
Participant Seven	31
Participant Eight	35
Appendix F: Interview Transcripts.....	40
Transcript One	41
Transcript Two	61
Transcript Three.....	77
Transcript Four	104
Transcript Five	132
Transcript Six	152
Transcript Seven	165
Transcript Eight.....	175
Pilot interview 1	175
Pilot Interview 2.....	183

**Appendix D: Letter of Invitation to
Participate, Letter of Interest to
Participate, Participant Information
Leaflet and Consent Form**

Letter of Invitation to Participate



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Letter of Invitation to Participate: A Study on How You Support Service Users with Autism in Participation in Daily Life.

Dear Staff Member,

This letter is to invite you to participate in a study to explore how you support service users with autism in participation in daily life. As each person with autism is different, staff knowledge and understanding is crucial when supporting service users in participation, communication and social contact through day to day activities. The Discipline of Occupational Therapy, Trinity College Dublin is collaborating with X Service in this study to find out about how you support service users in their day to day life

All staff members are invited to participate, including care assistants, social care workers, relief staff, community employment staff and management staff. As the setting of the service might make a difference, we are looking for the opinions and views of staff from all areas, Residential Service, Day Services, Outreach and Maintenance Services.

The study involves each staff member volunteering to engage in one interviews of 30 – 40-minute duration. The interview will explore your thoughts and opinions on how you support service users in participation in their daily routine, in communicating his/her needs, in social contact through activities such as meal times, and in his/her hobbies and other meaningful activities.

You can choose not to take part in this study in any way. The decision is entirely yours and will not affect your employment in X Service. Your identity will remain confidential. You will be given an identity number. Only the interviewer Siobhan MacCobb will know which interview transcript/identity number belong to which participants. All data will be anonymized before it is given to the researcher, Aishling O'Reilly. Your name will not be published and will not be disclosed to anyone working in the service. All data collected will be stored securely and confidentially for five years and then destroyed.

If you are interested in this research project, you may contact me by text or email, or leave a letter of interest in the box labelled 'Aishling O'Reilly: Research' in the meeting room in Apartment 3, on the Fairview campus site. An information leaflet with further information about the study will be made available to you before recruitment for this project begins.

We would really welcome your contribution.

Yours Sincerely,

Aishling O'Reilly
Oreilla8@tcd.ie
086 – 1448724

Dr. Siobhan MacCobb (Supervisor)
smaccobb@tcd.ie

Letter of Interest to Participate



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Letter of Interest to Participate

I am interested participating in this research study. Below are my contact details with which I give permission to the researcher to contact me and arrange a time and date for my first interview.

Name: _____

Contact details:

Number: _____

Email: _____

Preferred location: _____

Availability: _____

Signature: _____

Participant Information Leaflet



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Participation Information Leaflet: A Study on How You Support Service Users with Autism in Participation in Daily Life.

Date:

Dear Staff Member,

Thank you for contacting me. You are being sent this Participation Information Leaflet because you have indicated that you are interested in further information about the study.

What the study is about?

As each person with autism is different, staff knowledge and understanding are crucial when supporting service users in participation, communication and social contact through day to day activities.

The Discipline of Occupational Therapy, Trinity College Dublin is collaborating with X Service in a study **to find out about how you support service users in their day to day life**. This study wants to explore how staff adjusts to the individual needs of the service users, and adapt the demands of the activity and daily routine so that the service user can participate. Ethical permission has been granted by X Service and the Faculty of Health Sciences, Trinity College.

What does it involve?

The study involves the staff member volunteering to engage in one interview of 30 – 40-minute duration. Notes will be taken and the interview will be audio-taped.

The questions are: 'Tell me about how you support a service user in participation in their daily routine; in communicating his/her needs; in social contact through activities such as mealtimes, and in his/her hobbies and other meaningful activities.

As we really want to get a deep understanding of how you offer support for the service user, further probing questions will be asked, as described on the interview guide.

The interviewer is a lecturer in the Discipline of Occupational Therapy, Trinity College with many years of experience working with services and people with disabilities.

Who is invited?

All staff members are invited to participate including care assistants, social care workers, relief staff, community employment staff and management staff. As the setting of the service might make a difference, we are looking for the opinions and views of staff from all areas, Residential Service, Day Services, Outreach and Maintenance Services.



How do I get involved?

If you would like to be interviewed, you are asked to contact the researcher Aishling O'Reilly by text or email. The researcher will arrange the time and location of interview as directed by you. You will be invited to ask further questions before continuing with the interview. If you still agree to be interviewed, you will be asked to sign a consent form giving permission for you to take part in the study.

A typed copy of the interview transcript will be sent to you. Seven days after your receipt of the typed transcript, a final consent form should be returned to me, thus giving permission for your anonymized data to be included in the research.

How is confidentiality assured for you and the service users?

As this research is about your work in X Service, and the researcher Aishling O'Reilly is employed as an occupational therapist in the service, particular care regarding assuring your confidentiality and that of the service users is built into the process. There are several stages to protect identity.

First, you will be given an identifying code number at the beginning of the interview. Only you and me, the interviewer will have access to the code. Your permission /consent form will not be coded with this information, codes and the permission forms will be stored separately.

During the interview, you will not be asked your name, age, or specific location of service. You will be asked not to refer to service users by name during the interview. The audio tape recording will be edited for any identifying information, such as the exact location of your work, your name, age and gender and other details that might distinguish you from another. This will be removed from the audio tape before typing of the transcript. If unique identifying reference is made related to a service user, this too will be removed from the audio tape before transcribing. The transcript will be forwarded to you for your consent before they are forwarded to the researcher Aishling O'Reilly.

What will happen to the information?

The interview transcript will be stored on a USB key and the audio tape will be stored securely in a locked cabinet for five years and then destroyed. The codes and the signed permission forms will be kept in separate locked cabinets for five years, in the Discipline of Occupational Therapy and then destroyed.

Your information will form the basis of a Master in Research in the Discipline of Occupational Therapy, Trinity College. An article may be submitted for publication in a journal. A summary report will be sent to X Service, should it be requested.



Do you want to contribute to this study?

Your views and opinions are important. Results of this study may inform how other staff could be further supported in making their important personal and professional contribution to service users' daily lives.

It is your choice to participate in this study. The decision to participate or not will not affect your employment in X Service in any way. Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone working in the service.

If you would like to make your contribution to this study, please complete the information on the attached page, giving your contact details and preferred location and time for a face to face meeting. I would welcome your contribution.

Yours Sincerely,

Siobhan Mac Cobb PhD. MSc. Dip. COT

Assistant Professor and Research Supervisor

Consent Form



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Consent Form

A Study on How You Support Service Users with Autism in Participation in Daily Life

Contact details:

Aishling O'Reilly

oreilla8@tcd.ie

Discipline of Occupational Therapy, Trinity Centre for Health Sciences, James Street, Dublin 8.

Academic Supervisor:

Dr. Siobhan MacCobb

smaccobb@tcd.ie

Discipline of Occupational Therapy, Trinity Centre for Health Sciences, James Street, Dublin 8.

Background

This study is being carried out to find out about how you support service users in their day to day life. This study wants to explore how staff adjusts to the individual needs of the service users, and adapt the demands of the activity and daily routine so that the service user can participate.

What is involved?

The study involves the staff member volunteering to engage in one interview of 30-40 minutes duration. Notes will be taken and the interview will be audio-taped.

The questions are: 'Tell me about how you support a service user in participation in their daily routine; in communicating his/her needs; in social contact through activities such as mealtimes, and in his/her hobbies and other meaningful activities'. There will be further probing questions as described on the interview guide, in order to gain a deep understanding of how you offer support to the service user.

The interviewer is a lecturer in the Discipline of Occupational Therapy, Trinity College with many years of experience working with services and people with disabilities.

The interview transcripts will be kept on a USB key and the audio tapes will be stored securely in a locked cabinet for five years and then destroyed. The codes and the signed permission forms will be kept in separate locked cabinets for five years, in the Discipline of Occupational Therapy and then destroyed.



Consent Form

Declaration: I have read or had read to me, the participant information leaflet for this study and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Please fill in the following if you consent to take part in the research project:

Signed: _____

Date: _____

Statement of investigators responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Investigators signature: _____

Date: _____

Appendix E: Participant Stories

Participant One

Participant one (P1) is a horticulturist and reported on how she works with one person in particular, who also loves the garden. P1 has been working within the service and with this one person for over twenty years. P1 works part time, offering some personal care support to a person in his home at 9am, and then works in the garden until 4pm.

What's in your head coming to work?

P1 describes *"my real job is, is the care but within a horticultural setting. So, definitely, I would see myself as using the horticulture every day in order to enhance people's lives. And to get the best out of them"*. P1 goes on to say that she begins thinking about work two days beforehand, *"Ehm, I'd probably start thinking about my day with him, maybe two days before I come in to work"*.

P1 explains how she is thinking and planning for how she will support the person to transition from day service to his home. She reports having to come up with a scenario to offer the person so that he will travel in the car with her and the transition to home can be a success;

"I would have to be thinking ahead and figuring out you know, what am I going to do. He particularly has had a problem with going home... it's that transition between going... I'd have to come up with a scenario where I'm lying about him going home. So, I could have to think about that two days before hand."

P1 is thinking about the logistics of the working day, such as transport and their schedule.

"So, I'd have to think about ok have we got a van available. Or, where are we going to go beforehand, and ehm. I suppose I would be starting to feel a bit stressed thinking about what if it goes wrong".

P1 states that they *"would have to put a lot of thought"* into preparing for the next day in work. *"So, when I come in I'm thinking ahead... How can I make this day the best for [the person]"*? But she is also thinking of her other responsibilities;

"The other part of my head is thinking, right, what have I got to get done today. Well, it could be you know, tidying up, weeding a particular area; cutting back something; planting seeds; ehm, harvesting vegetables; ehm, planting up baskets. So yeah a lot of the horticultural kind of stuff".

Hobbies and Interests

"So, I've been working with one person a lot, and ehm, he loves the garden. So, that has meant there's a real team. So, he loves the garden and I love the garden and I feel it's a good match for the two of us".

P1 further describes the persons skills and how she supports him;

"And he's fantastic physically at gardening. Awh yeah. You know. Amazing strength. Very good dexterity. Safety conscious wouldn't be great now, we have to mind that bit. But ehm, wonderful skills. So, it's kind of, allowing him use those skills as much as he can".

She states *"I want to give him the opportunity to be"*.

Routine

P1 describes her daily routine with the person, starting at their home and travelling to the place of work, the garden. P1 expresses a conflict, where they are trying to encourage him to start work;

"I started this morning at his place at nine. But, he wasn't ready to leave until eleven o'clock we didn't get out until 11. So, then I'm down there trying to encourage him to work, and he's having tea and coffee, and I'm standing".

The researcher comments how the person seems to be in charge of the routine. P1 affirms this interpretation and comments on the ethos of the overall service;

"Oh, he is, and that's always the way it is... and I suppose, a lot of our service users would. And I suppose that's the way I feel the ethos of [the service] is. That we are there to work alongside, and to provide them with the structure that allows them to be the best they can be".

Communication

P1 depicts communicating with the person she is supporting, *"you're all the time mimicking what you would like X to do"*. For example,

"So, if I, you know say it's cold. And I'll mimic putting on my coat. Ehm, then he might do it... it's a lot by association and mimicking. And maybe mentioning authority, [like when you want him to put on the seatbelt in the car] you might be, 'Oh is that a guard?' You know, and then he might put on the belt".

P1 uses questions as a prompt to support the person to do something;

"Questions, with [him], [like] 'where is your toothpaste?' Do you know. Rather than saying 'brush your teeth'. You know, 'I can't find the toothpaste anywhere?'

You know, you do that 'he knows better than me' kinda thing. Ehm, 'awh, I don't know where the kettle is'. And then that might prompt him to go fill the kettle".

In this way, the person is not being directed to do a task, something that P1 states is stressful for him, but the question is enough to prompt him to engage, *"Because if you use too much verbal with him, or if you suggest or if you tell him to do something, that's a no no".* P1 then discusses how communication between staff is important,

"I suppose reading the report to see what happened the day before, that can be the basis of conversation. You know, and then when you're writing your report you're trying to add in as much detail so that if [he] said 'my friend', you might be able to say 'oh he met Mr. Y yesterday', because he may not be able to say who, the name".

Staff support his communication with the next staff on shift, so that the person has continuity. Support staff know from the report what happened the day before, *"Yeah, a lot of anticipation, a lot of knowing the back story with what's gone on".*

Social contact

P1 spoke about how the person she works with has rich social interactions with his co-workers in the garden. *"See on the day that he's here with us then there's lots of, there's a good few work people around, like maintenance staff. So, he has a lot of banter and he has a lot of chat".* P1 has a role in this, by supporting co-workers to learn the best way to communicate with him;

"And there would be that subtle thing of informing people that low arousal is best with [him]. Ehm, but yeah, a bit of banter. You know, so we might have had a couple of CE workers we work with, yeah... that you might have to, you might have to have a word and say ehm 'don't argue with him', you know. Or, yeah.

P1 has observed the persons relationships with his co-workers develop over time, with both parties getting used to each other and co-workers altering their communication style to suit the person;

"And you can see over time people get used to that with [him]... you don't use the bad language, you don't do that bawdy kind of talk that you might have in other work areas. Or, not in work areas but you know maintenance, kind of... and they they do get used to that".

"And then it's at the same time, [he] gets used to people not being so straight laced with him either. You know... it's just getting used to him and him getting used to other people".

Participant Two

Participant two has been working as a Community Employment staff in the service for the past four years, with core responsibilities being gardening and maintenance. However, P2 has set up the Men's Shed in the service and has been facilitating activities and providing that space for up to seven people for the past two years.

What's in your head coming to work?

When asked about what is in your head when coming to work, P2 responded with,

"The big question, right, you walk up that road. I find thirty seconds after walking in that gate, a certain feeling comes over me yano. Just the tranquillity of the [place] just takes over for me".

"I ended up putting five bags of daffodils around the place. Right and the thinking behind it was that on a cold dark Monday morning your coming into work and when you see the daffodils around, they it will lift your spirits a little bit and when your spirits are lifted a little bit your able to help the service users

Hobbies and Interests

"Eh, you kinda (pause) look, look and observe right and see the way all of the staff treat them and the staff goes on and I just pick up on that and the service users, they'll tell you, yano, what they want if you ask them... would you like to do this"

P2 describes how a person will say yes or no when offered an activity choice. P2 also describes how he notices if the person shows curiosity in something he was doing. *"If they're curious yano and if they come over, and just start talking about the weather, and all that, and [I suggest they] do this, and it just takes off from there... I work on their curiosity".*

Routine

When discussing their role within the service, P2 states, *"the best thing I can do is support the staff"*. P2 expands on this, with a solution to supporting staff through their daily routine, in order to better support the person with autism;

"I'm involved there in the Monday club or the Men's Shed and I'd, I'd, depends on who, which service users are there, right. I'd say to staff you go ahead and do your paper work, right. My way of thinking is right, if they can get the paperwork

done. Right, now when the lads are finished, the staff have more time for them yano, just, and that's how, just support them".

Communication

P2 uses body language as a method of communication, reading people as they walk in the door of the men shed, *"Body language yeah. The lads that I do be with on a Monday nearly tell me the way they walk in the door, where they are. You can have a pretty good idea alright".*

He explains that he also uses expressions to communicate with people, by observing their face and doing their face back, or making a happy or sad face and looking for the persons reaction. *"I use a lot of expressions. I show a sad face. Yeah. And they'll pick up on that... and... If they're happy, then they smile with me, laugh and joke with them".*

Social contact

P2 describes the social contact that occurs during the Men's Shed comprising of *"generally, four [people] but it can go up to seven and there's one female that might come down".* P2 states, *"it works"*. P2 gives an example of how he sets up an activity of making stone slabs so that this social contact can happen, *"Now I make up the slabs and the two lads they work well together. One will hand the stones to the other fella to put it in yano"*.

P2 describes another person who comes to do some work in the garden every week, referring to another person who joins him as *"his partner fella"*. Gardening or maintenance activities that require side by side or turn taking partnership were explained with the main purpose to offer the social engagement of working together within the environment of the garden.

Participant Three

Participant three (P3) works in a residential service with five people with autism. P3 works twenty-four-hour shifts, alongside *“two staff on the overnight, and for the last few months we’ve got three staff on, for four of the days”*. P3 affirms that the people he supports are all individual and unique, and states that *“it can be challenging”*.

What’s in your head coming to work?

P3 describes how he prepares himself for work, including the practical aspects such as packing a bag and travel;

“Well really preparing for work starts the day before because we do 24-hour shifts... So, really, what I’m thinking about is what’s the weather like for the cycle. And, hopefully not forgetting my keys because most of the doors are locked in the house I work in”.

“It starts with the logistics of getting in and making sure I have got you know a change of socks you know to get through the day. It really starts with the logistics of work before I even start thinking about the lads”.

P3 does not think about the people they will be supporting until they receive a handover that morning. *“Ehm, really the first time I start thinking about what form the lads are in, is when I come in and the handover takes place at 10 o clock”*. P3 gives their reasoning for this thinking;

“Until then, there’s no point in having any preconceptions because somebody may have had a bad day when you were in the day before. And they may be in flying form the next day”.

P3 report feeling a responsibility not to carry the previous days negativity into the next shift, *“So, there’s really an onus not to bring any, you know, yesterday’s negative to tomorrow’s shift”*.

Hobbies and Interests

P3 describes a previous job they worked in where they supported people in their hobbies and interests, by offering experiences and observing what people like. The researcher asked does P3 do the same thing within this residential service. P3 responded, *“Yeah. I’d try that as much as possible”*. P3 describes a barrier to working in this way within the residential service;

“And, I said that we had a staffing, kinda issue, in that we were very thinly spread... it means that as there’s more paperwork to do since HIQA came in, that there’s less and less time to actually do what the guys want to do, and what might help them feel more fulfilled, or, what I personally like doing is helping a service user surprise themselves”.

Here, P3 describes a conflict between what they want to do, and what they are expected and supported to do, by HIQA and the organisation.

Routine

P3 portrays the variability of the day to day job with, *“there’s really, ehm, there’s no standard hour per day”*. P3 goes on to depict the general pattern, or routine of the day, regarding the places they may go;

“There are standard patterns of what we do, I’ll often go out with a couple of the lads, go for a walk, where there’s not a lot of distractions, a beach, or yeah somewhere in a park where there aren’t you know lots of cafés or shops...”

The routine is used as a way to keep people regulated;

“Ehm, so there are patterns of what we do to get the guys out of the house and help them feel more relaxed and there are clinical plans around some of it so that they use up energy and sleep better so they’re not like relying on medication for sleep”.

Communication

P3 states that there is no general approach to communicating with the people he works with, as they are all so different.

“There can’t be a general approach, because... one person can speak and articulate what [they] want, one can speak but won’t generally speak much, because he finds it difficult to physically speak. Ehm, and one has four words that I know about, including hi and bye”.

He continues to explain that staff have to be very careful when communicating with the person, that they do not ask leading questions and that they listen for how the person says something rather than what they say.

“And ehm, another service user speaks a lot but much of it is echolalia, and he will often say, yes when he means no... And, sometimes, he’ll repeat what you say, so you have to be careful not to ask leading questions, or if you did, when you see

him becoming confused, you have to, instead of listening for the word he says, you have to listen to how he says it”.

P3 explains that he sees challenging behaviour as a form of communication and provides an example from his working day;

“So, I’ll approach somebody smashing stuff in a café as, OK, immediately we get out, make sure everyone’s safe. But, it’s a form of communication. Sometimes it’s for an underlying reason, sometimes it’s just purely impatience because they’re waiting for somebody, another service user to do something. And, so, often, five different people sharing the same staff becomes a conflict of, I wanna do this, I wanna do this. The fastest way out of a café is to start smashing it up. And that’s the simple communication”.

Social contact

When discussing social contact, P3 provides an example from a previous job within social care, where he facilitated two people to connect *“as humans”* through making music with a drum. He would set up two seats beside each other to encourage the two people to sit beside each other, and slowly added to this by adding a drum and pulling the chairs closer together and closer to the wider group.

“The biggest outcome for me was not any of the musical development. Some of the people started, you know, coming you know quite good with the shakers or having great fun with the drums. But it was the social development, and people with disabilities often don’t see any social value in other people with disabilities because they can’t get them their food, their drink, their rewards. So, they don’t, they don’t see the social value that, of the interactions. Whereas it started happening naturally in the music circle. So, it was like a form of occupational therapy, because the occupation... was, making noise... and then the people started viewing each other... You know, as humans... It was incredible”.

Participant Four

Participant four (P4) works in a residential house where the ratio is *“two staff to five people”*. P4 has been working in the service for approximately five years and previously worked within the business sector. P4 states *“I love this work”* and *“I love being the key worker with the guy I’m working with”*.

What’s in your head coming to work?

P4 states that first he is thinking about the plan for the day, and their efforts to accommodate each person within the plan, *“Ok, yeah well now the five... we have a plan, for each day where we try to accommodate every service user to the best of our resources and abilities”*. P4 is thinking of the plan for the day, and then the organisational things such as who needs to drive and what staff are on shift,

“What’s on your mind is... you’re thinking of OK, what day is it today, who’s going where, who am I working with, because... we have a lot of relief staff, and there’s a lot of staff who don’t drive, so you end up doing a lot of driving. Eh, and so, then you know, ‘when will we fit this in with everything else?’

Ultimately, P4 describes what they are thinking and hoping when coming to work, *“So, what’s on your mind when you’re walking in well it’s ‘I hope I get a good run with somebody today’”*. However, P4 goes further to explain the reality of what can happen day to day and the type of responsibilities that take priority;

“I really hope... but then you come in and something has happened. Somebody needs a prescription somewhere, you need to bring somebody to the doctor, you need to do this and do that and suddenly, all the lovely stuff of, of, of, supporting them in goals and activities and tasks gets put on hold”.

Hobbies and Interests

When asked by the researcher about how hobbies and interests are supported, P4 reiterated that there are five people living in the house and stated that staff try to accommodate them each to the best of their ability;

“Well, now, yes but, now you see we have five service users. Ehm, there are two people working with them. That’s ok. Yes, the support end of the job, as in looking after them, from advocacy, to, to their health care, to all between medical and social.

P4 discussed how staff tasks impinge on their ability to support people fully in their hobbies and interests;

"I mean the cleaning and the cooking and the lists of that end of things, between food preparation, food management, cleaning of the house and everything, can take, it eats into everything. Also, money counting. Little things like that and writing in the daily reports... What's happening is... that you're not getting enough time to do the other part of your care work, as in, interacting and supporting the guys".

Routine

A picture of the daily routine is provided above in the description of how staff support people's hobbies and interests, where P4 describes the tasks that must be completed throughout the day, *"there's tasks. Our tasks"*. P4 further touches on how a person's own routine has been impacted by service protocols. P4 gives the following example;

"All he wants is, maybe have a lie in in the morning, get up at lunch time or a little bit before lunch time, have a shower, come down have his lunch, have his breakfast in his room, come down, and then ehm maybe in the evening, because he's never, he doesn't want to get up, you see, in the evening time then he likes to have his dinner and he loves to say 'will we go for, can we go for a cup of tea and a muffin?'... Can't do it".

Due to a protocol around staffing in the house, this person is not supported to carry out his routine as he wants, which is to go out in the evening with one staff member. P4 describes that when advocating for the person and his wishes, management do not respond with a solution that is meeting the person's wishes;

"Now, and then you'll get the answer back, 'well bring him out in the morning time or in the afternoon', no. That's not what he wants. And it's not his, it's not, do you know?"

P4 later expands on this topic of the person's routine in conflict with the service's routine, giving the example of the de-congregation of day services and the effect this has had on people's routines;

"Up to, about two years ago they stopped... and another guy in the house for 20 years were going from here every morning, and over... to the day centre. And that was their life, right. And then that was all stopped with the new-fangled get into your community, no more going to congregated settings, day centres. Wonderful put it up in lights!"

P4 conversed with a service user after they had made the transition, about how they like their new life, their new routine, *"So, I said... 'how's it going your new life and everything?'"*. He answered, *"I miss my friends"*.

Communication

P4 describes how he communicates with a person they work with, explaining *"He doesn't answer directly really, and you just have to let it come and go"*.

Social contact

"We used to have a bus and now we have a little car that only seats one two three, three in the back and one in the front, four. We can't take them all together anymore. We used to be able to go... Somebody said at a meeting there recently and I thought it was an interesting thought, again, this all sounds right. 'Ah well we're stopping all those driving them in buses together and you know it's not good for them. It's good for them to go out on their own or individually or in pairs and all'. Is it?"

P4 reminisces on when they used to travel together on their bus, *"Because by golly when they're in that bus and they're all together <there's craic>, and they did it for twenty years!"*. P4 describes the scene of the people together on the bus and how they were social together,

"That's what they did. And they listened, one guys listening to the music and they, and it's not 'awe we're all together', it's not. It's autism. They're on their own together. It's a very extraordinary thing".

P4 further describes one person who doesn't like a lot of one to one interaction but very much likes to be part of a group;

*"There's a guy that I work with there and he, you look at him, you'll say 'hey how are you doing', *disapproving grunting*. Put him in a little group... He likes being in the group... Don't look at me. Don't talk to me. Don't come near me"*.

Participant Five

Participant five (P5) has been working with adults with autism for three and a half years. P5 informed the researcher that this was their *“first job in social care”*, as they previously worked within a different sector. P5 is working with people who are living in their own homes, and would see two to three people individually, per shift. P5 works *“like a twenty-four-hour shift, so start at 10am, do a sleep over then that night, and finish up at 10am the next morning. But as well as that I would do a couple of ten to sixes throughout a certain week period as well”*.

What’s in your head coming to work?

P5 discusses the importance of being aware of boundaries when going on shift, *“Boundaries is a big thing... Like, if you kind of go in on shift, one on one... you have to have your boundaries up you know, they will railroad you, like”*. P5 continues to describe how your own form may affect the kind of day you will have with a person;

“If I come in to work say and I’m in good form, myself you know, all is well with me in the world, I can have a good few hours with the lads you know. Whereas if I’m coming in a bit stressed, it can be, it’s like as if they sense it, yeah it can be tough, it can be a tough few hours, for sure”.

P5 affirms that how you prepare for work is *“very much an individual thing”* and states how his staff team *“would lean on each other quite a bit, I suppose for peer to peer support”*. The effects of staff stress on the work is described;

“Where, possible, you know if you’re feeling a bit stressed your own common sense goes out the window a bit as well. You can end up in a kind of, an argument or, going down the rabbit hole a little bit with the lads”.

Hobbies and Interests

P5 initially reported having reflected on the question relating to hobbies and interests prior to the interview, *“Well, eh it’s interesting I was thinking of that one as well in a question”*. P5 described the people he works with and how they don’t receive support with their hobbies and interests,

“So, there’s [a number of] guys that need overnight support and we would be with them throughout the day, quite a bit. There’s other guys that are living out in the community on their own and they’re kind of living their own lives. And we would

link in with them on an outreach basis. So, as regards hobbies, they're kind of self-sufficient. They're kind of doing their own thing... yea".

P5 further describes specific interests that people have and how they engage with them independently;

"They would generally do their own thing, yeah ehm. Like one of the guys would be into a lot of IT stuff, which I wouldn't really have much, like, they'd be nearly guiding you... I wouldn't really be up to speed on that sort of stuff you know. Like some of the guys then they're in gyms, yeah, they go independently".

Routine

When asked if staff support the persons routine, P5 responded with;

"Yeah, we're only there really to kind of help them with different... So, one of the guys... He has a job. He wants to change career. He's not enjoying his [current job] ... And he will come to you and say will you help me, you know maybe like doing up a CV, things like that".

P5 stated a difficulty that they come up against when working with the people they support, *"I'm not ready to do anything". You know, I think a lot of the lads they're not really good with change or moving on to some other stuff".* P5 continued to discuss what staff actually support the person with, referencing independent living skills and housing;

"Well what we will do is independent living skills would be a big thing you know. So, the guys who are living out in the community, we would help to source them a place to live first of all, you know maybe contacting landlords and going to viewings. And speaking on their behalf because they wouldn't really have the skills maybe to do that themselves... get them rent allowance, kind of linking in with the community that way. Setting up bank direct debits, you know..."

P5 then describes the routine that the staff and the person have together, which is described as functional;

"Then into the kind of I suppose day to day managing a place to live, that kind of cleaning, cooking, you know setting up direct debits for bills and utilities you know that kind of thing. But you know to be fair, that's been done for most of the lad's a while ago now. But really when you do meet up with them it's kind of more functional I would say. It's kind of gone, as I would have said, a little bit of stagnation there".

Later in the interview, P5 reports on the day to day routine providing insight into the staff's work, cooking and doing the person's laundry, saying, *"We have to cook... they*

don't cook". P5 describes how he may try to encourage the person to do their own laundry, "which they're able to do... And they're just like 'no, I won't do that, that's not my job".

Communication

The researcher asked P5 *"you don't really have to support them in communicating their needs?"*, to which they responded *"No"*. The researcher confirmed once more *"they can communicate their own needs?"* to which P5 responded *"yea"*.

Social contact

The researcher asked if P5 supported people in social interaction or engagement. P5 clarified, *"eh so in that sense now, with other people in the community?"* and then affirmed, *"Sometimes yea"*.

Participant Six

Participant six (P6) is working within a day service that is in a period of change, where a larger day centre is being split into separate Hubs. P6 works with service users from before 9am until approximately 4pm and then staff are allowed to go home after seven hours, as they don't get a lunch break during the day. P6 states that *"there's only three staff for six lads"* within the day service.

What's in your head coming to work?

"So, coming in to work, so, obviously you think about, what the lads, kinda, cause we would have ehm timetables which the lads have kinda scheduled out. So, you'd kinda know briefly, like, if the lads want to change their mind, they're entitled to change their mind".

P6 describes anticipating how a person is going to be once they get to work.

"So, for preparing today, you'd kinda say, Ok. Like I know with one service user like, if the weather is quite bad, you're kind of expecting to have a not so great day because the weather would really affect him".

If they know to expect a person to be upset, they need to prepare themselves before coming to work, *"so, if it's raining, then you just kind of prepare yourself"*

Hobbies and Interests

When asked about how the person communicates their wishes regarding hobbies and interests, P6 responded that people will verbalise likes and dislikes;

"Ehm, yeah like from what I, like, they would, like they'll say what they like, and what they don't like. Our lads would have, ehm. Like, one service user would be very, he would know exactly what he wants".

P6 highlights the importance of supporting the person to explore new activity options;

"You know, he would be very adamant of, so trying to kind of bring in new activities into his schedule. And to try to open his mind up as well, because I think as well with autism, it's very... very routine. And, there's kind of, they need to get those kind of choices in to build on their interests and hobbies".

A consequence of not providing this support is given, *"Otherwise they'd stick to the same thing for the rest of their lives".*

Routine

P6s comment on the person's hobbies and interests, relates also to routine and the person sticking to the same routine, possibly *"for the rest of their lives"* if they are not supported to explore new activity options. In addition, P6 refers to the routine being directed by the person, with staff checking in if they are happy with their schedules;

"So, we do like a Voice and Choice every week... So, they would come down and kinda express. We'd ask how do you think your timetable is going? And, is there anything that you would like to do? And, so, that's how they'd normally get their voice across. And then, like if the lads don't want to do an activity, they'll let you know they don't want to do the activity".

Communication

P6 states that *"the six lads that I personally work with, are very, are all verbal"*. P6 explains how they recognise that someone is in bad form;

"Ehm, with direct communication, like maybe you could see if, ehm like for one service user, if he's kind of a little bit snappy, a little bit out of sorts, then that's how we would kind of know if there's something up".

P6 describes offering emotional support to the person in a chat and allowing the person the space to express themselves;

"And then we'd sit down and we'd have a chat about it. But, one service user, he's actually having a bit of a stressful time at the minute. But he's very vocal and he's able to express himself... I'm listening yeah".

Social contact

P6 describes how they support one particular person in social contact when out in the community and how they support him to manage his own socially inappropriate behaviour;

"Ehm with that typical service user we have ehm, boundaries would be very good, for him. Or, a lot of inappropriate kind of behaviour of wanting to see ehm, maybe tongues and stuff like that. Ehm, so we'd do him a social story".

P6 describes the content of the social story, relating to his special interest in cars;

"So, there'd be a social story of 'out in the community'. And ehm, 'what way we act', cause he loves cars. Really really loves cars and would, you know kind of go up very closely to look in. whereas someone might get the wrong idea, that he's looking in".

P6 gives the person something else to focus on when out in the community;

“So, that’s a, we just kind of said, maybe when we go out, we don’t look into the cars. Maybe we could have a, just keep walking and you look after yourself and mind yourself as you’re walking down. So, it’s to kind of put the focus in on himself and be aware more of say the roads, and road safety and stuff like that”.

P6 would use social stories for a lot of the people they work with, *“So, our social story is our kind of, way of going out into the community to reduce that for a lot of our service users”.*

Participant Seven

Participant seven (P7) has been working within the service for six years, and within outreach day services for three years. P7 is based in a 'hub' in the community where the people attend each day and work on individualised goals. The people who attend would have gone through the special school system. P7 states that the work involves working with people on a one to one basis and also in small groups of maximum three people. P7 states *"We are lucky... We have the option to do both"*.

What's in your head coming to work?

P7 describes what they are thinking when coming to work, relating to who she is working with and what they have planned for the day;

"OK, so like usually, who is in today, like because it can be you know, there are some movements between houses, but which service user is going to be in. What's their plan for the day. Do they have any plans? Because some of them would go to a course, or they would have something going on. So, what's their plan".

In the event that P7 knows the person doesn't have a plan, they are thinking what the person's choices are;

"Or if they don't have a plan, what kind of options can we, you know, offer. Or, what could they do. Or, what could we work on. So, that's in my mind first, and then they come in and it can totally change".

P7 states that once the person comes in, they have the freedom to change their plan; *"you know, like if eh, you know it's up to them basically"*. P7 describes how they are planning for supporting the person's goals or activities and setting up the activity before they arrive, *"Usually yeah like I just try to think, what's going to happen on that day and if something needs to be prepared, I can prepare it for them before they come in"*.

Hobbies and Interests

P7 discussed how staff can support the person to change their routine so that staff can *"try so many more things"* with them. P7 discussed thinking about the persons goals and activity options for the day, and how she plans for this engagement;

"I would prepare I dunno like sheets for him. Or, if I know that, that his goal is to work on I dunno like money management, or relationships. I would try to think of exercises or ideas where we can actually practice".

P7 describes how she supports the goal setting process, with the person wanting to go to London, but she needs to support the planning and the steps involved in achieving this, such as *"planning it financially... applying for a passport"*. P7 explains that a person's goal *"comes from them and from us as well... he might not necessarily know that you know... he needs to do these things. It's me who explains the things, you know like 'ok that's great you have this big goal, but then we need to do this and this and this so that you can achieve that'. So, it's kind of a mixture"*.

P7 describes how the person is so capable, once they are given the steps in how to go about a task, then they can do it for themselves;

"With him you need to help him with the steps that help him achieve something... He is very capable. So, he can do anything, anything he wants but he needs that extra bit of support. Just for the steps".

Routine

When asked if supporting people's routine is an important part of her work, P7 said *"it's so hard to answer this question"*, because for *"some service users yes, some service users no"*. P7 concluded that *"in general, yeah, some of the service user's routine would be important for them"*. P7 discussed how staff support the person in their routine, and how sometimes *"we try and support them with their routine or even changing the routine, you know"*. P7 states that most of the people she works with are flexible relating to changes in their routine, *"But ehm, most of them would be quite flexible, actually"*. A change in environment was found to be an enabler when supporting someone to change their routine,

"I think it's really interesting, there is a service user... in the past we thought that he would be really you know, ehm he needs routine, he needs his schedule and stuff like that. But, since he comes over here, at least once or twice a week, we realise that actually he's not that stuck with his routine, he can be totally flexible".

The change in environment allows the staff to try new things with the person's routine. In addition, P7 refers to the staff also being stuck in the routine in the previous environment, *"We can try so many more things here with him than in the other house where we were, you know, really stuck. It's is a new environment for him, new people around and he's more, flexible"*.

Communication

When asked about how to support people in their communication, P7 stated that it takes time, and they get to know the person first.

"So, again it takes a while. It depends, so like if we have a new service user, or everyone basically... my approach would be to get to know the person first, spend time with the person, have like you know, have ideas what could work".

P7 reflects on the people she works with and how they communicate, concluding that everyone communicates differently;

"But, like here it's a bit different like each house is a bit different, so like this house would be more, you know, ehm. Actually, it's a mix if I think about it. So, like everyone is so different here".

P7 states that most of the people they work with are verbal, however they need extra support to process and understand what's being said.

"So, ehm, but yeah most of the guys would be verbal so they would, would be ok to understand, you know, speech. Eh, maybe some of them need, maybe you need to be slower, you need to speak maybe a bit slower. Or, you need to make more simple sentences".

In addition, some people use visuals to communicate, *"Or, with some guys in the other houses we would use visuals"*. Later in the interview, P7 is describing how they support the person with achieving their goals, and they expand on their use of communication using repetition and writing;

"Lots of repetition, if I do talk to him it's always repeated, 'So, X, you need to leave, what time do you need to leave your house, to get whatever?'. And then I ask him again and again, and he gets it, but it's more repetitive. And I found writing down things for him helps, so I don't have to keep repeating myself over and over".

"But anyway, it's up to the person and it's really individualised, I guess".

Social contact

P7 was not asked directly about social contact, but when discussing goals, the topic arose. P7 described the great difficulty it can be when supporting people to access their community in a meaningful way, *"Our goal is to try to you know, integration and you know, be in the community. But, it's so hard because the community is not always open*

for the guys to do things or to try things". P7 describes supporting a person on Job Shadow Day, and later attempting to support them to volunteer in the same pub;

"We did the job shadowing day... And he was in a pub. And he was amazing like he recognise, like he can remember everyone's name, like straight away. Like he was eh, you know, pouring the, he did the taps and stuff like that. He loved it! And, ehm yeah so, we tried to get like maybe an hour or two hours per week, for him. Like maybe first just to volunteer, whatever, so not, paid, you know. But, no".

P7 offers a possible solution to the barriers people face in social inclusion, rooted in educating the public about autism;

"I find that it's a bit difficult. But again, it's, maybe just people need a bit more education about what autism is. Because it seems like they get scared, or they have this stereotype in their mind and they just straight away say no, 'Oh we don't need anyone now".

Participant Eight

Participant eight (P8) was working in an Outreach Day Service with adults in the community, who have gone through the mainstream school system. She had been working in that service for one and a half years. She works eight hours a day, consisting of *“two individual sessions or if there was a group, probably one individual session and a group could be anywhere from two to six or seven people. Depending on the day”*.

P8 completed two separate interviews as the pilot study for the research. The first interview focused on what the participant does to support the people with autism in their day to day lives and lasted 15 minutes. The second interview focused on why they worked in such a way with the people they support and lasted 14 minutes. Following this pilot, it was decided that one longer interview would be more efficacious.

What’s in your head coming to work?

P8 completed two separate interviews as part of the pilot study for the research. The first interview asked straight forward questions about how the participant supports people in their hobbies and interests, daily routines, communication and social contact. The second interview focused on the why they worked in such a way with the people they support. P8 went on to explain reasoning behind supporting the person with autism in their daily routine;

“Ehm, well I suppose the things about routine, would be about giving more responsibility to him to organise and plan things. And the real reason behind that is so that he can actually learn to do that for himself and I suppose, not feeling like the service is doing him a dis-service by showing up, and for him to expect that when you’re meeting someone [a staff member] they just show up. Eh, no when you’re meeting someone you kind of have to agree a time, and you kind of have to have contact with them and you have to be there on time, or else it doesn’t really work.”

P8 is considering how the actions of the staff are focused on preparing the person for real life situations and relationships. The actions of staff are all related to the persons goals, *“Ehm, thinking for his own life, his goals are he wants to get a job and he wants to move away”*. Therefore, going into a session, P8 is trying to imagine how the person would be if staff were not present, *“I suppose trying to think about, trying to think if you weren’t there”*.

Hobbies and Interests

P8 supports people with their hobbies and interests *“through individual sessions or groups”*. P8 explains how they offer support to a person in an individual session by first finding out what they are interested in;

“it’s with one person so you would explore their interests with them first and see what actually they are interested in doing. One guy I’m working with at the moment wanted to try out baking, Ehm... so that’s something he’s doing at the moment within his individual sessions within his house, and trying to get used to using the kitchen, following the steps and everything else”

P8 discusses how often this exploration might happen, and then how they facilitate the exploration, and how knowing the person well is important for this to be successful;

I suppose we’re lucky in our service that we know them quite well, so we might have this exploring every couple of weeks or months. It’s not so much a first interaction... from getting to know them you can kind of come up with your own suggestions as well because sometimes they might not think of it off the top of their heads”.

P8 describes different ways of exploration, either through having *“one of those conversations of, you know, is there anything you’re interested in doing”, or*

“an interest checklist is helpful because sometimes you ask them and it’s a bit of a hard question to say is there anything you’re interested in or do you have any goals. And I’ve found one particular person you could ask him that and he’ll just say ‘Oh I don’t know there’s nothing really I can think of. And then if you did the interest checklist there was 10 to 15 things that actually he really wanted to try and get involved in”.

Staff seem to have a role in facilitating the exploration by providing ideas and expanding on things that the person is already interested in, *“I suppose suggesting things to them as well like dye know there’s people who are really interested in music but, sometimes you might have to suggest what about getting involved in volunteering or what about this?”*

P8 describes some difficulties in exploring hobbies and interests, relating to the person’s imagination and how a written checklist provides a solution to this barrier, *“So sometimes it’s that imagination or not being able to think of something but by having something like that makes a big difference”.*

Routine

When asked about how they support people living in their own homes in their daily routine, P8 explained how the service can support the person in their own routine. The service structure has changed;

"We used to kind of give out people's hours or their sessions and just show up to their house at that time. That was kind of how the service was set up. And recently with one guy in particular... this was happening and we just felt like he didn't really have a concept of time or routine. It wasn't really within his control, people just showed up and then you did whatever and then they'd leave again".

Now;

"we ask him to plan the sessions in advance and now we don't really go to his house unless there's a reason. So today I went because it was baking... otherwise we say we'll meet out in the community, because then I suppose he has to, first of all plan it in advance, second of all, figure out what time he actually has to get up, have his breakfast, do his other things."

The routine of the service is driven by knowledge of the person's own goals and learning needs;

"Because he really struggles with that kind of time management piece and planning and organisation. So, I suppose trying to support him in that because we really felt like by me showing up to his house at a certain time that doesn't give him any of those skills to actually have a routine then later if he wants to do other things, he ends up late or he doesn't know the bus to get".

The staff support the person in planning their day and organising themselves;

"Some of that you actually need to have a session before the session: OK what time are you going to leave your house and what time are you going to have breakfast and what bus are you going to get then and where are you going to meet them?"

The staff are facilitating the person to have *"more control over [their] time... Rather than it being more passive which I think it was for a long time"*. The staff are thinking of the person's future;

"Trying to get them better at structuring their own routines and for things like if they have an appointment in town or someone else to meet you can have a bit more confidence that they might be able to do that".

Communication

The population that P8 works with are all *“verbal, so they can tell you what they want to do but there are different ways still to support it”*. P8 describes how even though a person is verbal, you may need to communicate differently in order to communicate properly;

“We notice that sometimes with people like you might ask someone something in person and discuss something but they wouldn’t have much to say... some people we support would actually communicate better by text or email rather than asking things in person. You know when they have a bit of time to think about it and then reply to your text”.

The service support this by using the work phone to *“send someone a text if you’re planning a session”* or to *“talk about something with them or suggest an idea over text”*.

P8 describes how people can have difficulties processing information, *“Even though they are verbal, you can over, I think, expect them to know, to hear everything you’re saying and to process it”*. P8 supports the person’s processing difficulties *“for meetings and things like that when you’re talking about a lot of stuff at once, I’d always have things written down as well”* and facilitates the person to communicate back by having *“an opportunity for them to write onto that document”*.

Social contact

“I suppose on our team a lot of that would probably happen through group work”. P8 explains that the team sets up social opportunities for their service users

“because I think a lot of the service users we work with one of their biggest barriers sometimes to doing things is that they don’t have someone to do it with, or they don’t have a lot of friends outside the service”.

The group work *“has been a really big positive thing on our team for social contact”*. P8 then describes their role within the group, where some people don’t need staff support, facilitating the group to work together is enough;

“some people who came to that who came and chatted and no bother you didn’t really have to do much prompting or, you know you didn’t really have that much of role within social contact other than having the group there”.

However, others do require support to engage. P8 describes one person’s personality and his faint presence in a group

“There’s one guy who would be more introverted, he’d kind of be in the other room it’s easy to nearly even forget he’s there because he’ll be in the other room, does a lot of self-talk, and doesn’t particularly want to engage that much”.

P8 describes how they include him through doing a task within the group;

“To remember to try and include him in some way, give him something to do, so say we were making a stunt dummy for the guys film that he wanted to do. And you know just asking him to come in we’re cutting bits of rope would you mind cutting a couple of bits of rope to this length”

This prompt is enough to set him up for interaction with others in the group;

“and then he comes in and he says ‘oh I think that stunt dummy is cool what are you making?’ and has a couple of sentences back and forth and then he goes back into the room”.

P8 touches on the idea that “everyone’s different... it really depends on the person” when supporting group work;

“Sometimes the group work just naturally gives the social contact but then for other people having that activity to focus on and bringing them in and giving them a specific role and asking them to do something and have a bit more of a role as a staff member, makes a big difference, and then over the weeks they might get more and more involved or then they start chatting to the other people in the group”.

Again, this statement shows that staff are thinking about the person’s future, by supporting them within the group work and having a view that maybe they can reduce that support over time.

Appendix F: Interview Transcripts

Transcript One

R: Ok, so really, what we're really interested in is what's in your head when you come to work <OK>, when you're trying to support people, or that kind of stuff.

P: OK.

R: Just to kind of warm us up, I'm asking questions about how long have you been working in XXX and have you always worked with people with autism? Just to give us a bit of background.

P: Yep. No problem.

R: So.

P: Oh. I've eh started in 1995.

R: Oh, wow. Yeah.

P: Yes. It's been a long time. So, is that 23 years? And ehm so yeah, I've been here since 1995. Eh, I initially was working full time, five days a week. I was employed as the horticultural care worker. So the horticulture is a large part of my job. I identify more as a horticulturist than a care worker. And, then once I had my first child I went part time. So, that was 1997.

R: So, what's really handy about that is that you've been here for so long you've seen a lot of change.

P: Yeah. A lot of changes. And, yeah, all, nearly all of them I'd say for the better, which is you know. Because I would have had time off after the babies, and then come back and there would have been another change. You know, different change again.

R: Yeah.

P: So, ehm yeah a lot of changes. It feels like I've been here a long time.

R: So, the big thing is, when you come in to work, ehm, what do you see as your real job?

P: I suppose that's changed over time.

R: Yeah.

P: My real job is, is the care but within a horticultural setting.

R: Yeah.

P: So, definitely, I would see myself as using the horticulture every day in order to enhance people's lives. And to get the best out of them.

R: Right.

P: So, I've been working with one person a lot, and ehm, he loves the garden. So, that has meant there's a real team. So, he loves the garden and I love the garden and I feel it's a

good match for the two of us. Ehm, I'd probably start thinking about my day with him, maybe two days before I come in to work.

R: Really.

P: Yeah. I would have to be thinking ahead and figuring out you know, what am I going to do. He particularly has had a problem with going home and doesn't, he would say he doesn't want to go home. So, for years we've lied about the fact he's going home. Now, his home is very loving, ehm but we know, once he gets there he's happy. But it's that transition between going. So, we'd have to do, I'd have to come up with a scenario where I'm lying about him going home. So, I could have to think about that two days before hand. So, I'd have to think about ok have we got a van available. Or, where are we going to go beforehand, and ehm. I suppose I would be starting to feel a bit stressed thinking about what if it goes wrong.

R: Yea, yes.

P: What if he refuses to go home? You know, so yeah I would I would have to put a lot of thought -. Especially on the Friday's. that's when he goes home. So I would have to think about all that. Ehm, in the past three months, three visits home let's say. We've seen a huge change in him <really> which is really enormous. Ehm, he actually thanked me for bringing him home recently. This is enormous like. And today he said to me 'will you bring me home next time?' Now he's very, limited speech, ehm, can't always think of the right word for things. So, you're kind of flowing with him and figuring out what do I think he's trying to say, and, and he said, 'I miss my family'. Which is just huge. And his dad reported having a really good Christmas visit with him. So, <really> so that feels great. Today, that feels just really well, really good. So, yeah. So, when I come in I'm thinking ahead. I'm thinking about how can I make this day the best for X.

R: Yeah.

P: And then, the other part of my head is thinking, right, what have I got to get done today.

R: Ok.

P: Yeah.

R: So you have two bits in your head. So, what do you need to get done then? What would those kind of tasks be?

P: Well, it could be you know, tidying up, weeding a particular area; cutting back something; planting seeds; ehm, harvesting vegetables; ehm, planting up baskets. So yeah a lot of the horticultural kind of stuff. So, there is times when you have to compartmentalise that. And, a lot of time with X, if he decides to mow the lawn well then

I can weed in that area. But, if he decides he wants to dig then we go dig in that area. So, you can't. So I have to look at the bigger picture of 'he's engaging, he's involved'. Rather than my own agenda of, I want to get this done.

R: Yeah.

P: That can be conflicting.

R: Yes. How much of a conflict is it?

P: Ehm, I don't know how to answer that actually. Ehm, I suppose I've been here so long and I know that my main role is caring, that I do have to let that side of myself go. The garden part of it has to go. Given the chance. I suppose I've been talking about, in work for ages that, I'm part of a Hub, right. Are you familiar with the way?

R: Yes.

P: So, before we were a day centre. And I was part of the overall day centre. And, there would have been, we all met, we all were a big group and there was a list made, and I would be down with gardening with two people. So, that was, I'd go gardening with that group. Now, we have divided into Hubs, and I've said I don't want to be part of a Hub. That I think I should have a horticultural job, separate to all the Hubs, and that people should come to me to do gardening tasks.

R: Oh, right.

P: So, that's not sitting well with management. So, yeah, it is, it is a conflict. And I suppose I don't feel my skills are being used to the best.

R: Yeah.

P: Do you know.

R: Yeah.

P: I think I could offer more, within the caring role. And, the horticultural role, I could offer more <yes, yes, yeah>. But, so yeah. It is a conflict, it is. And I keep beating that drum and saying to management, I think I would be better if I was separate to all the hubs and all the apartments and people saw me as, you know, the specialist I am in my own right. Ehm, I'm not hoping to work less hours, I'm not do you know, shirking responsibility. But, I, but they're not seeing it.

R: Yeah. And that would mean more people would get to do horticulture

P: Yeah, like sessions. Because at the moment, I'm with X so, for example, I started this morning at his place at nine. But, he wasn't ready to leave until eleven o' clock we didn't get out until eleven. So then I'm down there trying to encourage him to work, and he's having tea and coffee, and I'm standing. You know. Of course, you could be lazy and think 'oh this is grand' you know. But, I could be doing a lot more.

R: You could. More people could be involved.

P: More people could, I could. If I was here at 9, I could have somebody from -.

R: Yeah. Who wants to be here at 9.

P: Yeah. Yeah.

R: Ok. So that's the kind of questions really, is, that's what's in your head. Ehm, and the very last question, like way down, we'll be asking 'do you have suggestions about making things better'. So we have a suggestion already, is about looking at that. And then I have more structured questions around supporting the person in their daily routine, and their communication needs and that kind of thing. So you'd probably be able to tell me some detail about how you support, you've just mentioned X, and how you support him then in his routine.

P: Yeah. Yeah.

R: So he seems to be calling the shots. He's having the cup of tea and he's not really ready, and-.

P: Oh he is, and that's always the way it is that you're kind of, yeah you're all the time mimicking what you would like X to do.

R: Ohm.

P: You know. So if I, you know say it's cold. And I'll mimic putting on my coat. Ehm, then he might do it. Or, in the car you might go, you know, because if you use too much verbal with him, or if you suggest or if you tell him to do something, that's a no no.

R: Yeah.

P: So, it's a lot by association and mimicking and maybe mentioning authority, you might be, 'oh is that a guard?' You know and then he might put on the belt.

R: Ah, the seat belt. Aww right.

P: Yeah. You know. Now there's been times I've had to pretend I've fallen in order to like. X isn't allowed into the day centre. Ehm, so all the time when I'm working with him I'm all the time bringing him back down to the sheds, focusing him more so on the garden than the day centre. So, ehm, yeah. I've had to do some very strange things at times.

R: It sounds it.

P: Yeah. Just to make sure he doesn't.

R: Yeah. You're anticipating how he's going to be, you know that he could be resistant.

You know you can't tell him so you have to mimic and think in advance.

P: Yeah.

R: Right. And he really does call the shots.

P: Yeah and I suppose, a lot of our service users would. And I suppose that's the way I feel the ethos of [the service] is. That we are there to work alongside, and to provide them with the structure that allows them to be the best they can be. So, so yeah I would feel that with X that I'm trying to. I don't want to antagonise him, I don't want to aggravate him it's all very low arousal, and yet I want to give him the opportunity to be. And he's fantastic physically at gardening.

R: Really.

P: Awh yeah. You know. Amazing strength. Very good dexterity. Safety conscious wouldn't be great now, we have to mind that bit. But ehm, wonderful skills. So, it's kind of, allowing him use those skills as much as he can. I must say I'm very fond of him. I'm very, and I suppose on a day. Like I've had occasion with other service users where I have been attacked. You know, we'd have days like that.

R: Yeah?

P: And I would go back to what did I do wrong? Because one of the forms we fill in as care staff, is about a behavioural incident report. That's the name of it. The form, is what were you doing just prior to that incident. Is one of the first questions on it, so that inference has always been, what could you have done differently? You know, how did you, what were you doing that contributed to this person having an outburst?

R: Yeah. Yeah.

P: Which, ehm, yeah. It has an impact on you. You know when you fill something out, just after being involved in an altercation.

R: And, how do you feel after the altercation?

P: Oh, awful.

R: And what happens then?

P: Ehm, sometimes there might be a debriefing but sometimes you'd have to ask for that. You know, you'd have to-. Yeah you'd have to build, build. Actually one time I had, and actually the first person I rang was my husband to say 'oh god'. I was in the bathroom balling crying and he actually rang my manager to say, 'take X off site for a while'.

R: Yeah.

P: You know. So, ehm, I don't, I don't know if that's just with [this service], or whether other care organisations are like that as well?

R: No.

P: But, that. Yeah, you have to mind yourself. You have to definitely mind, you know as a carer <yeah> you have to mind yourself.

R: Yeah. And what about your sort of leaders or your supervisors, would they mind you?

P: *Pause*. I think if you, it wouldn't be an automatic thing.

R: Yeah.

P: I think if you, I'm a very, I'm quite emotional and I wear my emotions on my sleeve, so, but I think if you were somebody who didn't, 'you're fine. That's fine.' You know you could be taken as, 'you're fine'. <That you are fine>. Yeah, you know, so. So yeah, so there is a lot of anticipation, ehm.

R: In your day.

P: Yeah. So you're having to think all those things, even before you come to work.

P: Oh yeah. Yeah. Yeah. And like, I only work two days a week. So, that's what I'm saying, on the days I'm not in, <you're thinking>, you're thinking ahead. You're thinking yeah, 'how's that going to go'.

R: Hmm.

P: But, yeah.

R: So, then more specific things like you were saying you do the cue with the putting on the coat with feedback. From a communication point of view, do you have to do anything special, or, to understand the other person, or, to read them, or?

P: I suppose reading the report to see what happened the day before, that can be the basis of conversation.

R: Ahhh.

P: You know, and then when you're writing your report you're trying to add in as much detail so that if X said 'my friend', you might be able to say 'oh he met Mr. Y yesterday', because he may not be able to say who, the name. Or, yeah a lot of anticipation, a lot of knowing the back story with what's gone on. Questions, with X, 'where is your toothpaste?'

R: Yeah.

P: Do you know. Rather than saying 'brush your teeth'. You know, 'I can't find the toothpaste anywhere?' You know, you do that 'he knows better than me' kinda thing.

R: Right.

P: Ehm, 'awh, I don't know where the kettle is'. And then that might prompt him to go fill the kettle.

R: Right.

P: You know, so, a lot of ehm. Yeah and he can get distracted, which is good. You can distract him easily about things. You know, so eh, yeah. A lot of mind things.

R: Yeah and then in terms of his personal care, would you be involved in that?

P: Not so much because I'm day centre. But, brushing his teeth in the morning would be something that we would do before we leave his place.

R: Ah, ok.

P: Yeah. So, that's, and then maybe, maybe deodorant. Maybe, cause-.

R: Because it's a heavy day. Yeah.

P: Yeah.

R: Yeah. So, now that he's in work and stuff, do you think about his social, and how do you have him connect with others, or would you think?

P: Yeah. See on the day that he's here with us then there's lots of, there's a good few work people around, like maintenance staff.

R: OK.

P: So, he has a lot of banter and he has a lot of chat. And there would be that subtle thing of informing people that low arousal is best with X. ehm, but yeah a bit of banter. You know, so we might have had a couple of CE workers we work with, <yeah>, yeah. That you might have to, you might have to have a word and say ehm 'don't argue with him', you know. Or, yeah. And you can see over time people get used to that with X. That you don't have the banter, you don't use the bad language, you don't do that bawdy kind of talk that you might have in other work areas. Or, not in work areas but you know maintenance, kind of. Ehm, and they they do get used to that. And then it's at the same time, X gets used to people not being so straight laced with him either. You know.

R: Yes because he meets new people.

P: Yeah. Yeah. And, and, ehm, it's just getting used to him and him getting used to other people. So, he would see people in roles. He would see me as, he associates me with work, but also a bit of caring. So, he'd talk to me a lot about his mammy. You know, and he'd give me a lot of hugs, and that kind of. So I think he sees me as kind of with two different hats on. That's the way he'd see me. You know. He'd put you in a box, he'd put people in boxes. You can see him doing that, you know.

R: And, how long do you know him?

P: Eh, well probably the twenty-two years!

R: *laughing*.

P: Yeah. Because he would have been in [a service] from when he was 10.

R: Was he.

P: Yeah.

R: So, that's why the horticulture might really be-.

P: The gardening, the farming definitely. And then he was, he went then when he was 10, residential. And then during the holidays, he started coming to us. So, he was XX the other day. So, yeah he probably was coming to us on respite holidays from about 18. We'd have him for two weeks in the summer. And then he eventually moved to us full time, I can't remember the date but he's been with us full time.

R: And is he given residence?

P: He's full time, yeah 24 hour, he has one to one all the time. He always has a staff with him. Him and one staff. So, he's seen as fairly high, ehm, he couldn't live in a group home. Do you know, so he's seen as one of the more, people with lots of needs within the organisation.

R: Yeah.

P: Ehm, and he was emergency, he was put into this apartment. Ah, it could be ten years now. But, it was an emergency situation they had to get him out of one of the group homes. Yeah. So, I really do feel we've given him a really good chance. And we've given him a lot of stability. Like, he's gone from breaking doors and punching windows and hitting people and causing injury to people. To being-

R: A worker.

P: Yeah. And he identifies as a worker.

R: Yeah.

P: Yeah. And a valuable part, you know. But, things are going to change.

R: Are they?

P: Yeah.

R: How?

P: His house is going 24 hours, probably at the end of the month, so I won't be working with him anymore.

R: What does that mean?

P: So, at the moment he has two staff. And they come on at four and finish at ten. And then we cover the day part.

R: Yeah.

P: So, we're there from half 9, until 4. And if his house goes 24 hours, his staff will be, he'll have his own staff all the time. So, it's a big change about to happen.

R: He won't be coming to horticulture?

P: He may not be.

R: How did that happen?

P: Ehm, I don't know. I think it's seen as best practice. It's not seen as, not best practice, you know, it's not best practice for two staff, ehm. There's some European Directive for hours of work? So, some of those staff work with him three nights a week, and some of them work four nights a week. So, that's that's not best practice. So, it's best practice to have a team of three working 24-hour shifts. Ten in the morning to ten the following morning. So, I don't know how it's going to go for him. I'm going to miss him. And, I think he's going to miss us. I'm hoping that there will be some allowance for him to come over to me seasonally. And maybe, <yeah yeah> I'm trying to see it as a benefit. I'm trying to see that it will mean. Well what I don't want is to end up back in the day centre. As in, just caring. Because really that's not, I don't identify as, that's not what I want to do. So, I'm hoping that they will, ehm, build in time that he'll come to me.

R: Yeah. Like you were planning that you're a horticulturist where people could come for sessions and do work or whatever.

P: Yeah. But, then I suppose they're trying to figure out what will his staff do. You know. So, that's management. They have to figure out <you're right>. Yeah.

R: It is.

P: It is. They have to figure it out. But I'm hoping they don't just do it on paper, go 'oh well, X doesn't need to come here anymore'. And therefore, [the horticulturist] will do something else. So, because I do really feel we've gotten to a really good place with him. See, about a year ago, a year and a half ago, there was a guy working here, Y was his name. and, he was fantastic with X.

R: Really.

P: Just fantastic colleague. Brilliant and, but him and X, he really worked on X. And he was with X maybe four days a week. He had even longer with him. And, then when, during that time when Y was here I had less time in the garden. So, in the past year and a half I've had all this time in the garden. Which just has been brilliant. And I think it's given X consistency. Ehm, so, I think, you know, a lot of groundwork has gone in to get him to this point, you know. And, he may blossom. It may be the perfect thing for him? But I suppose, it's trying to figure out my ego in relation to that. You know, my ego of wanting him to be here so I can garden.

R: Hmmmm, Ok.

P: You know.

R: Ok, right.

P: That's conflict.

R: Isn't it. That's conflict.

P: Yeah that's conflict. I just have to figure that bit out. But, ehm I'm trying to look at the bigger picture and go 'it's probably for the best'.

R: So, do you work with anybody else?

P: Not at the moment.

R: So, you're going back to being a carer.

P: Not in the past year and a half. Well this.

R: Well, which you don't. You want the plan, that you have a resource, you're a horticulturist, people could have sessions with you.

P: Yeah. So, I could end up back in the day centre. See I am a driver as well. I drive the mini buses. So, I could end up doing the swimming trips and you know.

R: And you're a horticulturist.

P: So, some mornings I do start at 8 and I do drive the mini bus for an hour and a half. But ehm, and I don't mind, I don't. And I suppose that notion of not being seen as, not blowing your own trumpet and wanting special treatment, or. But its, see, eh you might hear that from other people as well saying, when I say to them, 'but I'm the horticulturist', they would say, 'but sure you can just show them how to do it'.

R: Are you serious?

P: Absolutely. Yeah. Sure ehm, we have a potter on site at the moment and she, amazingly talented sculptor, and she wants to do something on the time I normally do. And, 'could she not just show you how to do it?'

R: No.

P: No, you cant! There's no, and I suppose maybe, does that come from autism, that there's no, they don't see us as individuals in some ways?

R: Really.

P: Management. No. On paper we're just staff. You know, slot in, no chance.

R: So, right.

P: Hmm. But X, I mean he is so interesting a character. And his verbal communication with him, a lot of the time less is more. So, the less words you use, the better. And, ehm, yeah you're all the time thinking of words that he associates with. You know, later, can mean just not now. You know, tomorrow, or yesterday could mean <anything> anything, in the past. Ehm, he sometimes talks about being sick, but that's a form of communication, 'me back is sore'. Or, 'I've a heavy cold', 'a cold', and you know he's, it's just a conversation piece that he's, he is expressing some kind of need, but it's not necessarily <a cold> a cold. He talks about his mammy quite a bit. His mammy died a year and a half ago. Actually two years ago.

R: So, back to more specifics then with him, when you want to plan him, plan to do things, you've already explained you have to do the thinking.

P: And sometimes not talking about the thing you want to do is how it happens. So, he kept saying, 'you come for lunch with me'. You know, and I said 'yeah yeah'. So, we got dressed up to go for lunch and he says 'No I'm not going'.

R: Oh,

P: So, then we had to pretend we weren't going for lunch. Then we did go for lunch. So, yeah. Sometimes the thing he says he wants and then he gets it and then he doesn't want it. So, a lot of the times we don't-. So, like, I went over this morning and he said 'work'. And I said, 'yea', I don't know if I even answered because I'm so used, I probably nodded. Ehm, yeah so you have to kind of, he is leading I suppose that is the thing for him. And then if you want him to do something that you know he doesn't want to do, as in go home or get in the van. Ehm, I have a Bluetooth speaker. And it's attached to me iPod. So, one day he wouldn't, I knew he was not going to get into the van. It was looking dodgy now. So, every time he moved away from me the sound went off. You know, because it was Bluetooth. So, when he went to go this way, the music stopped. So, I said, 'if you come over here, hop in the van you'll hear the music'. You know, so, sometimes you have to use props, yeah you know, trying to figure out. And technology as well. Trying to you know. A certain sound track I'd often play 'Take That' in the mornings. So, that sets up a certain ambience, a certain <yeah>, you know just feel to the day. Now he did say to me after about four months, 'boring!'. And I thought, OK.

R: You're bored too yeah! So, what do you play now?

P: Now we don't have any music. You know. Now it's ok, there's no music there.

R: Yeah.

P: You know. But, and it's probably realising that he's moved beyond that.

R: Yeah.

P: That we don't need that anymore.

R: Yeah.

P: And listening to him say that, 'boring'. You know. We don't need it. Ehm, like today we needed to put rubbish away. And, before I might have said 'will you put the rubbish in the bin'. So, today I just handed him the bag, you know, and said nothing. And he'll do it. So I do think he gets confused by too much talking.

R: Yeah. Yeah.

P: Which is kind of hard cause I talk.

R: So, you spend the day not talking?

P: Could do.

R: Oh my god.

P: Could do a lot of, or you listen to him. No he chats, he might chat away. You know, ehm. Ah, he'd say to you 'chat, too much'. You know, and if there's other staff around he'd give out about us chatting too much. So And, he's got more tolerant of that as well. You know, we say we're just having a meeting. And, ehm, he loves funny things too.

R: Really.

P: He loves, he has a great sense of humour. He opened, we were emptying the lawn mower and he, he, I was taking it and he put the handle, he put the motor back on. And so, all the grass flew all over me. Now, it wasn't dangerous <yeah>, it could have been if I had, and I let a scream. And he just started laughing and he said, 'you were soaked with the grass'. And I knew what he meant, he meant covered, but and he would go back to that. He likes that daftness, you know.

R: Yes.

P: Or he, he took my key by mistake. And he thought that was really funny.

R: Yeah.

P: So, sometimes you have to make a scenario where it's funny.

R: Yeah.

P: You know. But, yeah working with him, it's all the time thinking, and thinking about how not to say something.

R: Yeah.

P: Yep.

R: Yeah.

P: Ehm, mimicking.

R: Yeah.

P: Repeating back what he says. Echoing what he's just said.

R: Yeah. Wow.

P: Yeah. And I suppose it's, like my manager came down one day and X was heading towards the day centre and I knew, so I said to him 'will you check for eggs!'. And it completely diverted him the other direction. Do you know, so you're, my manager said to me 'that was the best low arousal I've seen in a long time'. You know. So you're.

R: Instead of saying 'don't go', you say, here's another one. You do diverting.

P: Yeah. Yeah.

R: So clever.

P: And I'd be aware of where he is all the time. Do you know.

R: Really.

P: Like you're just, you're listening out. Now, this is a funny story. But the bathroom here, is horrible. It's the one down here that we use, cause he's not allowed go beyond the green gate. So, I have to keep that locked. So, I do have to say to him, 'don't lock me in. You're not to lock me in the bathroom'. So, he locks me in the bathroom.

R: He does?

P: He does. Right. And, I'd be saying 'I hope you didn't lock that door'. This is while I'm going to the bathroom, 'I hope you didn't lock that door. If you locked that door'. But he's outside giggling. But that's.

R: Your little fun. And he allows you go to the bathroom.

P: Yeah. So, then I know where he is.

R: Yeah. He's laughing at ya.

P: He's laughing. So, then what I do is, I go really silent, and he thinks I've gone. And he opens the door.

R: Are you serious?

P: Yeah and he opens the door. You know.

R: So, for you to get to the loo, and keep an eye on him you have to say, don't lock me in. and it's a big game, he locks you in, giggles and you know he's there.

P: <He locks me in>. Yeah. And, even over the past few months I'm not having to do that as much. You know, ehm, I might still say it and he won't lock me in. You know what I mean, and he'd laugh but.

R: You have a thing.

P: Yeah, you know, you just have to, yeah. But, Y as I said, Y who worked with him put in loads of ground work and would have given me loads of tips on X. Loads of things of you know don't ask him directly; don't tell him; make a game; make it fun. But respect him. Like, he doesn't like tomfoolery all the time. You know <yeah>, it has to be.

R: It's very, sounds like a real relationship.

P: Yeah. Yeah. I've definitely seen him, like his dad was saying he definitely can see a real maturity in him. And, I do honestly think that it's a way he has made us handle him. Do you know?

R: Yeah.

P: You know. So, that we've listened to him. Ehm, we could have handled him, that's probably not the right word. But we could have managed him in a different way, antagonised him and, you now, wound him up, and all those things. Ehm, he has a stacking problem. He stacks all the time. DVD's. And, he'd, his bed, he only has this

much room on a double bed, cause he has got DVD's everywhere. Ehm, we would see, when he's more anxious then he stacks higher.

R: Ah.

P: Ehm, and he loves buying new things. He keeps buying new DVDs and things. So, that's something else the staff have to manage with him. But, I, I don't, I never buy things with him. So, that's his relationship with me, we don't buy. And, I don't bring him into shops to buy. Ehm, or if we're in a shop he knows we don't buy.

R: Really? Wow.

P: So, that again is relationship. Yeah. But the stacking now is, eh. But the rest of his apartment is sparse. They don't allow him have anything else, anywhere. Because there's that encroachment then, you know, so his room is busy, but everywhere else is very calm.

R: And, does he stack in the garden?

P: No. He would hoard a little bit in the garden. He has his office. We gave him his own office. So, he would often put things in there. Oh, three televisions were in the dump and he put three televisions in his shed. So, while he wasn't here, we took them back out. And he looked for them. Ehm, and there's XXX who's in charge of maintenance, so we said, 'XXX took them'. So, there would be a bit of, you know, hierarchy there.

R: Yeah.

P: And he, he'd take it from XXX. He's accept it from XXX. Yeah.

R: Yeah.

P: But XXX I feel, I don't need to have that really authoritarian, I need to be a bit more easy with him. And I was trying to keep those lies and those, you know things that you're controlling them, it's like choices within limits, you know <yes> so giving him choices but ehm, yeah. I did a parenting course called ehm, eh, what was it, it was very good I did it years ago. And it was all about that conflict resolution kind of stuff and about you know, choices within limits. And, ehm, being respectful, but giving boundaries. So, I think that definitely stuck.

R: Yeah. And he seems to be doing so well.

P: Very well. Really really well, like you know just.

R: And now there's a decision. Has it been talked through with him?

P: No. no.

R: And what about your client centred piece here? And your support plan?

P: No. I think it's been put forward from, I think from a staff point of view. I feel.

R: Yeah.

P: From his. And I do recognise, you know I have no idea what it's like working with X in the residential setting. No idea. I feel sorry for the staff there, they have no internet in the building. They have no television. Ehm, and they're isolated. They work on their own with him, one to one. All one to one. They don't, they can't even really come up, rarely up here they don't even have any,

R: Chat?

P: No. And X sometimes doesn't sleep. Do you know. He might go to bed at four.

R: Right.

P: But, yeah no as I said his communication is, is ehm, it has improved. It definitely has improved over the past while. Ehm, for a while they were recording everything he said. All the phrases he said. You know, so that kind of, we have that book there to look back on, to see. And again, XXX would have put a lot of work into that. That was his baby he was recording every phrase X said. So, yeah no, he's good. He's definitely come on well now.

R: Yeah.

P: around communication is there more specifics?

R: Well no, it's just all seems to be tuning in, tuning in, tuning in. So, from a sensory then, from a more general sensory you'd be aware of what he can tolerate, what he can't or?

P: He's very tolerant, of, ehm

R: Yeah. Noise? Lights?

P: Yeah, he's ok. Ehm, probably sometimes doesn't seem to feel the cold and heat. Do you know so in the summer time he might <you have to remind him>, have three or four jackets.

R: Oh god.

P: And that's very difficult to manage cause ehm,

R: Getting them off.

P: Getting them off can be difficult. So, it can be, again I think there could be more management around that. There could be more clothes put away.

R: That he doesn't have access to.

P: That he doesn't have access to them. But then, that's seen as limiting, as being <a restriction>, a restriction. Ehm, sometimes, what works with X is the newest thing he got, is the thing he'll wear all the time. So, that might mean, buying him a new t-shirt at the start of the summer. And that might mean that he wears that. Or you'd probably have to buy two of the same t-shirts, three of the same t-shirts cause he'll want the same t-shirt all the time.

R: Yeah.

P: So, that's managing it again he doesn't like changing them, because he likes man united colours. So, but again lately he's been allowing them wash them, which is great. You know. Ehm, noise, people's voices shouting, that would attract him to it, but not upset by it. Food, he'd often, he doesn't like fish. But sometimes, you know, if somebody said, 'oh that's chicken', and it could be fish, he could eat it. Ehm, sometimes he just isn't hungry in the morning and he doesn't want breakfast. You know the way the social norm is we'll have breakfast. He doesn't want breakfast. He tends to eat much later in the evening. He's put on a lot of weight in recent years. And they're trying to, but it's like when he eats. He seems to eat late.

R: Yeah. And you don't burn it up then.

P: Then when he's not sleeping well, I think he's not, yeah.

R: He won't sleep well.

P: You know when you're tired, you tend to eat. So, he eats when he's tired.

R: The carbs. He hasn't got the sleeping routine right.

P: Yeah, and when he's home, his dad seemingly puts him to bed at nine.

R: And he goes.

P: And he goes. Lights are completely out. The dad has told me this. Lights are out at nine. His dad works as a XXX, tends to go to bed at nine and up at four. When X is home he doesn't go to bed, he doesn't go to work I mean. And X, with this visit home he was home for a full week, while the dad had the option, if there was any problem, bring him home, bring him back, ehm and he said X was, he said, I think he actually used the word 'enjoyed' his time.

R: Isn't that lovely.

P: Yeah. Enjoyed his time with X. Ehm, so sensory no he's not overly. Again the heat thing can be awkward, or cold, he didn't want to wear his second coat. But then he saw somebody else wearing a boiler suit, so he wants the boiler suit. You know, so there's that identification as worker, high-vis, work trousers, work boots, definitely.

R: You have him well sorted.

P: Yeah.

R: So, is there anything that you think would help? So, you've already said, from your point of view, for that. For X, decisions are being made that doesn't include you <yeah>. And, then secondly, you and your resources as you've said, how you really could be used a lot more with your skills, so more people could benefit. Other than that, is there any other kind of suggestions you'd have?

P: I think, his staff need more support, his residential staff need more support. And I think there needs to be opportunity for them to discuss <yeah>. Because individuals can go off and do things, eh. There has to be recognition that the stacking is part of X, and the more anxious he is, the more he's going to stack. I think we need a bit more education around that stacking. A bit more of the psychology in it, you know. Ehm, like somebody put a picture on the wall, and that stopped him stacking because he wants to see that picture.

R: Oh my god. So clever.

P: You know that? You know. And that was just fantastic. Now, the stacks came to the floor, but maybe a new rug might make him not stack? You know the way.

R: Yeah.

P: There could be something.

R: Yeah. Yeah.

P: He tends to buy the, like eh Kill Bill, that film. He has about seven copies of Kill Bill. <Gosh>, Because every time he goes to the thing he goes 'awh I love that movie', and probably has forgotten. So I think there needs to be a bit around, letting him buy but taking away.

R: Yeah, yes.

P: So, and yeah, I think, yeah. I think everyone keep talking and keep realising and recognising how well he has done. He has done so well. Ehm, and the consistency, I am worried with the consistency changing, because I have brought him home every time, it feels like maybe the last seven visits. I've brought him home. It could be longer it could be more. And as I say my anxiety starts two days before hand.

R: Yeah.

P: 'Awe, how am I going to do it, what's going to happen?'. Because what would happen is, when you're driving, previously now he'd go 'no! No home! Back back!' and he, and like you're driving the van on the m50 and you're feeling,

R: Yeah, 'this isn't good'.

P: And, Y would have always said to me, 'he'll only shout once or twice'.

R: Really.

P: And then, but trying to get me to realise OK he's only going to shout once or twice. And in the past he has banged windows in the van, he'd never grab the controls or anything that has never been something he would do, and he'd cry sometimes, you know, when he sees you going home. But, eh, that confidence to know, OK,

R: It will pass.

P: It will pass yeah.

R: Bit like life!

P: Yeah! And being honest with him, I'd love to get to the point where I was being honest with him.

R: Hmmm.

P: And I mean that's trust, him trusting me. So I'd often say to him 'I'm not bringing you home today, do you think I'm bringing you home? I'm not bringing you home. I promise you, I'm not bringing you home today'. So, on the days I am bringing him home, I never say that. Ehm, I might avoid his question. But I would really would not lie to him. Or, when he says where are we going? I would say I'm just going this direction. 'why are we going this way?', 'I just want to have a look at something'. Whereas now, in the past probably three times since I brought him home, the minute he asks that question, I answer him truthfully. Ehm, 'I'm going to [place name]'. Ehm, 'why?', you know he can say that, and I'll say, 'I'm going to see,' I'll mention his dad, the name. And prior to that again, XXX and I, the fella with the white beard, we'd build that up. We'd start mentioning dad earlier in the day. We'd start mentioning family, and just slowly infiltrating all the conversation in.

R: Yeah.

P: You know. Now we, funny, what happened was, one day I brought him home recently. And it was the wrong day.

R: You didn't.

P: I did. And I had to go back and get him.

R: You had to go back!

P: Yeah. I was so embarrassed. When we got there, his dad said 'I wasn't expecting him', and I said, 'I'm so sorry, I'll take him back with me'. And he said 'leave him, he's fine he's fine'. But then I rang staff and they said 'no. The staff are on for the whole weekend with him, we can't leave him'. So, I had to go back. So X got a great laugh out of this.

R: Did he?

P: He thought it was really funny. He thought it was hilarious, 'you got it wrong'. So, you know, he loves that notion that you got it wrong.

R: Yeah.

P: Ehm, so he would say to me sometimes, 'awe no dad's away, daddy, Scotland'. You know. And I say, 'look, we'll just go see if he's home.' Ehm, so yeah, I was reading, there's a, his profile, he has a booklet about himself and I was reading it this morning. And, his

dad says in it, "I really don't feel we've seen the best of X yet". And he says, "Just wait for it, just wait for it".

R: What a lovely thing.

P: Oh, amazing. "Just wait for it", he says, "he could shine yet". You know, so. And that notion of potential, I suppose. Do you know, that there's still a chance. So, I suppose improvements would be to keep X to the forefront, keep recognising that he does identify as a worker and as a gardener. And it's very important for his self-esteem.

R: Yeah.

P: Because, X either dresses in work clothes, or suits.

R: Oh.

P: So, he doesn't really do casual. So, he would see the prop as being, 'oh I'm a worker', or 'I've got a three-piece suit on'.

R: Right. Well thanks for that it's very illuminating. It's very deep.

P: Yeah. And I suppose when you work it every day, you don't, you know,

R: Think about it.

P: Yeah.

R: Cause you're just doing it all the time, you're thinking thinking thinking.

P: Yeah. And I do think it's, well I, there's other people in my life who I have to support and you know, in similar kind of ways, ehm elderly people. And it's that notion of ticking all the boxes. So, you're ticking the hygiene, you're ticking the work, the self-esteem, the socialization, the medication, X doesn't, but ehm, yeah you're all the time trying to fit that whole thing in to the whole lot, you know. So yeah, no it's been great to talk about it.

R: Oh, so skilled. It's so skilled.

P: Have you done some work yourself with people with autism?

R: I would have been in and out of XXX.

P: Ah right, yeah yeah.

R: And I would know some people who are, on the higher end of the spectrum who are adults. We would have run groups. But, ehm, the people are so different.

P: They are. On the,

R: Yeah. It's just so complicated.

P: I just did a course on Future Learn, Future Learning have you come across it?

R: Yeah yeah.

P: On understanding autism.

R: I don't know, I don't know how you understand it. They are all just so different.

P: And they were questioning, is it a thing. That was their question, is it a thing? How can you say this person is at this end and that.

R: Yeah, it tells you nothing.

P: Yeah you can't do it on a scan you can't do a blood test, you can't do it on genetics. So.

R: So different.

P: Yeah.

R: But you have your man sussed.

P: And he has us sussed too.

R: Which is the relationship piece, <yeah> the relationship's beautiful. Look how he's grown. Very much, and you'd kind of be thinking about that mother child thing. He's got that reciprocal, you know it's the 'I do this bit, you do that bit, I take my turn, you take your turn <yeah>. It just sounds like a gorgeous, a gorgeous relationship.

P: And I suppose it's about going beyond that stage though <you are though>. I have to allow him go.

R: He's now a teenager on, and he's now leaving that.

P: Yeah. And I suppose it's me recognising that myself, I suppose that it's, <maybe he's yeah>, you know maybe he's ready to move on and transfer those skills.

R: But. It'd be nice if he had the choice.

P: Yeah.

R: Or at least some contact with the past.

P: Trying to figure out whether he'll be able to have that, it's trying to figure out will he be able to make that choice. Will he have the capacity to make that choice. Ehm, I suppose I know him very well.

R: He needs the practice of both, like.

P: Yeah.

R: It would be lovely that he could come back to you for sessions.

P: Yeah. That would be good.

R: Awh. Thank you so much.

P: No bother.

Transcript Two

R: So the big questions. Really were trying to get ehm an idea of what's in a person's head.

What's in your head when you come into work? What way do you have to be thinking so that you can work with the people you work with?

P: Sigh

R: That's the big question

P: The big question, right, you walk up that road

R: Yea

P: Right <microphone noise>

P: I find 30 seconds after walking in that gate

R: Yea

P: A certain feeling comes over me yano

R: Yea

P: Just

R: Yea

P: The tranquillity of the <place> just takes over for me

R: ahhhh

R: Yea

R: See all those plants, coming in the gate and you think what head bangers are in here

P: No

R: There lovely aren't they

P: I put them all out

R: there absolutely gorgeous

P: Yea they're, that's all mine

R: They're yours

R: Yea X was telling me. So you come in and you have that tranquillity

P: Ye it took me a while, a while to recognise it, right

R: Yea

P: Two year ago, three year. X and the other gardener right asked me to get a bag of daffodils

R: Yea

P: Right

R: um

P: I ended up putting 5 bags of daffodils around the place. Right and the thinking behind it was that on a cold dark Monday morning your coming into work right

R: Um

P: And when you see the daffodils around they it will lift your spirits a little bit and when your spirits are lifted a little bit your able to help the service users

R: Yea

P: And it kinda grew from that and a void came here and one of the gardeners left so I stepped up to the mark

R: Um

P: I'm just a CE worker I'm not employed by the company

R: oh right

P: Void, Filled in the void right and started chatting up stuff and looking up stuff and

R: Yea yea

R: And then when you go to meet the service users that you work with, what comes into your head then?

P: eh, to me they're not service users. They're service users, yes, I know they're service user's yea but I don't treat them like < service users>. Yea.

R: So what does that mean?

P: just treat them like one of the lads

R: They're one of the lads yea

R: And how do you get to know the way that everybody talks or support that they need. How would you get to know what way people tick?

P: Eh, You kinda (pause) look, look and observe right and

R: Yea

P: see the way all of the staff treat them and the staff goes on

R: Yea

P: and I just pick up on that and the service users, they'll tell you, yano, what they want if you ask them... would you like to do this

R: Yea um

P: They will either say yes or no

R: Um

P: or if they're curious yano

R: Yea

P: and if they come over, and just start talking about the weather, and all that, and do this, and it just takes off from there

R: So you'd be doing a task, you'd be doing planting or something and people come over to you is that it

P: Yea

R: And then they're curious

P: Curious

R: And you just

P: I work on their curiosity

R: You work on their, work on their curiosity

P: Yea

R: And then would you just point out things, or give them something to do or

P: Ask somebody what they would like to do. Would they do it.

R: And they just get stuck in

P: yea

R: Right

P: It's (pause) the way I look at myself here is, right, ultimately, we have to do the job the staff is doing here

R: yea

P: The best thing I can do is support the staff

R: Right umm

P: Yano

R: yea

P: I'm involved there in the Monday club or the Men's Shed

R: Um

P: and I'd, I'd (cough) depends on who, which service users are there right, I'd say to staff you go ahead and do your paper work, right

R: Right, yea

P: My way of thinking is right, if they can get the paperwork done

R: Yea

P: Right, now when the lads are finished, the staff have more time for them

R: That's right, that's right, that's right

P: Yano

R: Yea

P: Just and that's how, just support them

R: Yea

P: in that way

R: Yea yea. And then the lads, how do you tune in to how different they are?

P: (pause) Don't, don't think about it

R: you just don't think about it just do your stuff

P: yea

R: Yea

P: (pause) I use a lot of expressions

R: Like? yea

P: I show a sad face

R: Really yea

P: yea and they'll pick up on that

R: Really?

P: Yea

P: (Unintelligible)

R: You do a sad face

P: I do a sad face

R: Umm

P: and (unintelligible) If they're happy

R: yea

P: then they smile with me, laugh and joke with them

R: so you tune in with their face and you just do their face back

P: Yea

R: yea

P: and if they just want to just sit down and chill out

R: and if they want to sit down and chill out that's fine

P: yea. And they comes down on a Monday and they do have music on in the, in the Men's Shed and just during the conversation yano, so 'what kind of music do you like?'.

R: Yea

P: and he named off a few things and I said is there anything else that you like?

R: um

P: and he talked for a few minutes and he goes yea I like UB forty

R: Really? UB Forty. Wow

P: Now you have to dig for it right, Took me now four or five minutes to dig for it

R: Yea. And it came up

P: So next week I had a UB Forty tape there

R: You did

P: Yea

R: Wow, yea

P: yano

R: yea

P: he never showed any emotions or any (excited noise) fun or that

R: it was there

P: it was there

R: Yea

P: Yano, I don't know if he remembered saying UB Forty to me but, told me UB forty

R: Excellent yea, so there's a lot of tuning in, in a quiet way

P: in a quiet way

R: yea

P: and that's the way I work yano

R: yea, which seems to work though

P: yea

R: less talk

P: less talk yano

R: um

P: sometimes, sometimes they don't want to talk. Fair enough, that's that's, a thing that helps me help them right is remembering that this is their home

R: yea

P: right and if I'm in their home

R: Yea

P: Look at it that way. Empower, I try to empower them

R: You're empowering them and they know it's their place

P: they know it's their place

R: So how do they feel looking at all the plants around the place?

P: I was in here on Saturday. I came in to eh put stuff away for the wind, the wind coming

R: oh yes

P: and one fella there came out to me, talking away there for about half an hour

R: Really

P: Right, and about the flowers. I said, 'what flowers do you like?'. 'I love the daffodils in spring'.

R: Really, yea

P: So I took him over where the daffodils were beginning

R: beginning to grow

P: Yea he had no interest in them right

R: Yea

P: He had no interest but he'd love to see the daffodils in spring

R: yea

P: so

R: yea

R: they do notice

P: they do notice

P: And the same fella, I had him up there. He was up at the front door and was planting flowers and there was old roller-skates right

R: Oh yea

P: And I picked up a roller-skate and I put a new flower into it and he went 'no no no leave that alone, leave that alone'. Right so, I explained to him what I was doing yea, right. I didn't hold the thing there and explain I'm going to take that out and put that in. When I was talking to him, I was doing it I was explaining it with me actions. Grand!

R: He could calm down then

P: Yea, right. But who ever noticed it

R: The roller-skate with the plant in it

P: Yea

R: Exactly, yea

P: To me, to me that's important

R: Yes it is, he did notice

P: yea. He wouldn't be able to turn around to you and say that's nice but take it away

R: he noticed

P: he noticed yea

P: And that's the way I

R: When you're setting up jobs to do, do you have to think carefully or how do you think if you said about people being curious and then other than that do you have to think about jobs that you think a certain person might like. Would you have a notion that somebody might like something?

P: yea I do and I set up things for, for each (pause) just one or two like to do painting so I organise stuff for them to paint, organise the paint and that for them to paint. One or two lads yano they pot up flowers so they hang baskets in there. During the winter I'm making up signs.

R: oh are you, making up signs?

P: yea for I've one there just finished yano eh "X Service", right. Make concrete slabs

R: Oh

P: And put the colour stones in it right

R: wow

P: Now I make up the slabs and the two lads they work well together. One will hand the stones to the other fella to put it in yano

R: Um

P: And me plan is put it here out on the front wall. Screw it to the front wall, but they know that that's theirs.

R: Um, they know it's their work

P: They know it's their work. Now they wouldn't, I don't think they'd ever turn around and say

R: that's mine

P: That's mine

P: If you asked them about it they might know, right. But Somewhere, Somewhere in their bin they recognize that that's theirs

R: yea, so you're picking out jobs that suit the painters or whatever

P: Yea and picking out jobs for that right and then transferring it to out there where they can see the work

R: They can see the work outside

P: They can see it

R: Yea yeah yeah

R: So from the kind of communicating point of you, you use your face or you use their body language kind of thing

P: Body language yea

R: And you don't have to worry too much about words and you get them tied into working together if you know they work. And are there other things you need to think about? So that things run smoothly

P: eh, no I don't think about it yano. Ok. I organise tasks right and if a problem comes

R: Yea

P: I'll deal with it

R: yea

P: Alright, but I don't expect. I'm not waiting for,

R: Yea

P: looking for not looking for problems right. The lads that I do be with on a Monday nearly tell me the way they walk in the door.

R: Really yea

P: Where they are

R: So when they walk in the door you can read them

P: You can have a pretty good idea alright and the carers that bring them down

R: Yea

P: Will say to you

R: Will give you a nod

P: Give you a nod, yea, right that's grand

R: And you start

P: yea

R: yea and you've your tasks laid out yea

P: yea

R: So, ehm, you know it all goes nice and chilled. People that want to sit down, they sit down. You play music that people might like and you have your tasks and do you get a sense that people really enjoy it?

P: Oh yea

R: yea

P: If I don't mention or if the time doesn't come up, will say one o'clock they will automatically go for lunch. If that time doesn't come into it they would stay there till 4 o'clock

R: You really would. They just really like being there

P: they like chilling out

R: yea

P: they'll say, 'oh chill out'

R: It's lovely

P: It is, it's good

R: Yea it is very calm

P: Two yer girls here during the summer alright

R: Yea

P: and I can't see anything special in what I'm doing, right, but them two girls were amazed with what was

R: happening, yea

R: Cause it's all done quietly you see and your thinking, your keeping it clutter free really.
 You have the task laid out, no push, as you say use your curiosity

P: I let them free to be free

R: Yea

P: if that makes sense

R: absolutely and then they just get interested

P: yea haven't had the Men's Shed since before Christmas

R: Yea

P: and I said to one of the carers, the Men's Shed is on on Monday, (different voice:
 Hopefully M has the biscuits ready to go, oh no, I should have bought two small packets of
 biscuits there not big enough)

R: packets of biscuits?

P: At the end of it we have tea and biscuits

R: Yea, so one of the lads brings along biscuits

P: he brings along biscuits

R: he brings the biscuits and he decided that

P: Yea

R: yea that's really nice and he wanted two packets

P: No there was two small packets

R: Two small packets yea

P: right but no he wanted the big ones

R: Wanted the big ones for the people having the tea

P: yea

R: Right so that says a lot

P: It does, to me it does

R: Yea it says it matters enough to be bringing a big packet of biscuits yea

P: yea, it's not greed

R: no

P: right, they'll all have three biscuits each

R: And they sit around

P: um

R: about how many people would be there kind of

P: Generally four

R: Yea a Lovely size

P: But it can go up to seven

R: Wow yea, In the Men's Shed

P: Um

P: and there's one female that might come down

R: Yea yea. It works

P: It works

R: It works. Is there anything that would make it better or is there any supports that would help to keep it going, or?

P: eh, I haven't come across that problem yet

R: yea it's ticking along fine

P: it's ticking along fine

R: yea

P: right, eh, if I come across a problem I go to [the occupational therapist]

R: really? Oh right

P: yea, right, there was a problem that (pause) we went out begging for donation for paint. Right we got that.

R: Right and where did you get the money from?

P: we didn't we went begging

R: just went and asked people for money for paint?

P: yea went out to [paint shop] and got our own paint

R: Really? Oh right

P: We went down to [paint shop] and got paint of them as well and brushes and things like that

R: um right

P: If I'm looking for, if I need to buy something I have to go and put it down to the garden right so. I'm looking for a budget for the Men's Shed and start going through what house uses it yano

R: oh yes

P: what house yano, who's using it? I said that doesn't matter. The whole place benefits

R: <place benefits from> the Men's Shed

P: yea

R: so did you get a budget?

P: it's only after Christmas

R: so you've only started looking

P: yano so

R: So there isn't <really a problem>, and if there is you can solve it <yea> yea

P: there's more than one way of skinning the fat off

R: So, your here about three years?

P: Four

R: Four years, and the Men's Shed is going

P: Two

R: Great, well established yea. It's really working.

P: yea when I started they were trying to put a structure to it

R: Really?

P: (pause) they wanted to. The instruction was to bring the Men's Shed out to, out to the world

R: Yea

P: Grand yea out into the community and my idea right, ok, yes, in time

R: Yea

P: But there is a big community here in [the service]

R: There is

R: With the outreach and things like that, bring them into it. Get that community strong right then you'll be able to push out into

R: Um you're right. You do have a good community, I mean, a reach of a community outside of this particular site. There is a lot of service users that could um

P: Its growing coming down here now

R: Yea

P: On a Wednesday I have two fellas, two lads, down the garden and how that started I was asked, one fella expressed his desire to work in a building

R: Work in a building

P: To work in a building doing labour. I was asked would I be able to, would I have any idea. I gave it a bit of thought and came back and said there is a lot of digging to be done, getting ready for

R: planting

P: for planting for next year

R: yea

P: He comes down now

R: Um

P: Wednesday is his day right

R: Um

P: We get stuck in no problem. He loves it

R: He gets stuck in on Wednesday

P: Yea he loves it. Hail rain or snow it doesn't matter

R: Really?

P: yea

R: He's working

P: He's working. We have great conversations and said what film he was at on Sunday and tell me the whole story about it

R: oh right (laugh) yea yea, he got that. So you can see how it can expand yea

P: Yea and the beauty about it is right that I suggested that he gets paid for his work

R: Umm

P: get's paid for his time. So on a Wednesday I'm given an envelope with a small amount of money in it. Right, the smallest paper money that you can get and that is

R: His

P: His

R: yea he's delighted

P: Delighted

R: right he's getting paid for his job

P: He's getting paid for his job

R: yea

P: and trying to work on slowly but surely chipping it away that it's his team not X's team it's his team and he's partner the fella that comes from outreach and something similar yano, they dunno what to do with the fella,

R: Yea

P: right they can't motivate him and he comes down to me on a Wednesday and within an hour with him I knew he done this before

R: really?

P: the staff didn't know that

R: really?

P: yea, I gave him a tool, a secateurs and he knew immediately how to open it

R: really, yea

P: he comes down on a Wednesday

R: right yeah yeah

P: and he comes from his home down here and he arrives here one morning at 10 o'clock. I do text his carers that he's here and he's gone yano. Must have got up out of bed early to come down

R: He must have been if he's down for 10 o clock.

P: 10 half 10

R: isn't that great

P: Yea

R: Yea it's lovely

P: lovely

R: yea

P: I let him drive the ride on

R: He drove the ride on mower yea

P: right

R: Yea

P: But going through a space he's looking back to see if he had enough space for the trailer to go through

R: Umm yea

P: Grand. Brilliant, yano

R: It is yeah, so there's definitely a whole thing that could be expanded

P: Whole thing

R: So is [the occupational therapist] the person then who would be able to do that, get more expansion?

P: Eh (pause)

R: Who would be kinda putting it out there?

P: (pause) Facebook

R: Really? Go on

P: yano Put photographs up of what the lads are doing

R: And give ideas

P: Give ideas for other staff

R: And the lads, yea that's a really good idea yea really good idea. So it is going well, so you don't have any other recommendations, well established

P: Getting established

R: Yeah it's fabulous

P: I'm here 4 years.

R: Yea

P: This is going on 2 years

R: Yea

P: Before that there was all of this. It was stuck, it was stuck in the past and

R: Old ideas

P: Old ideas right

R: Yea

P: And then when the new direction was introduced yano certain people don't like this, don't like this, yano

R: umm

P: maturing yea, and with that came [the occupational therapist].

R: Ok

P: Right

R: yea

P: Totally different way of going on than anybody else here

R: right, yea

P: So with [the occupational therapist] and eh [previous manger] right, the two of them just blossomed, right, and everything else underneath it started blossoming

R: Really?

P: And that's how I got here, yano

R: yea

P: These, these people yano (cough)

R: Getting it

P: Getting it, right, cause we're on the same, same wavelength right

R: Yea

P: We like, a flower puts a smile on people's faces

R: and it does

P: you mightn't see the smile but you know it's there

R: Yea and the lads really like doing the work

P: Yea (pause)

R: Right, well good for you. It's great to get a chance isn't it and to see it grow

P: Yea

R: Yea like it is, it's lovely

P: See that growing, see the lads growing there

R: yea, shows you the, what work can do and what gardening can do and what just being with other people in the right environment can do

P: yea, the only complaint that, the negative that I feel yea right where your coming from right,

R: yea

P: A lot of the graduates coming out of there, yea don't like the idea of getting their hands dirty

R: yea

P: thinking I didn't go to college to do that, yano

R: No, but when you look at something like gardening or painting or any of that, the way it's done means so much to people

P: yea

R: yea

P: [the occupational therapist] brought this. If [the occupational therapist] had, was afraid to get her hands dirty, none of this would be

R: happening

P: yea, yano she just doesn't sit there behind the desk writing and puts

R: No, she wants people doing things that matter and are meaningful and enjoyable and with other people

P: and she'll get up and do it

R: yea

P: and I think that is... the getting out and doing it

P: yea

R: ok, that's important then for feedback, the getting out and doing it

P: the getting out and doing it. When I started here my job was to keep the grass cut, right and somebody asked me one day yano about six months into it asked me 'why do you do it, I said 'it's simple' right. If the grass is all overgrown and things like that then the residents haven't got a choice. If the grass is nice and cut and neat then they have a choice to walk on it or not walk on it

R: They do, they really do. Your right, they have a choice to walk on it or not walk on it

P: Right say the old way, eh the staff, did nothing outside

R: They really did nothing outside?

P: Stay indoors yano it might be cold out there, playing on me phone

R: Really?

P: yea, I thought they were afraid to go out or they didn't like it or what but I don't think they ever got the, how garden can be therapeutic

R: It really can be yea, and do you think that's changed now?

P: Yea

R: Yea

P: Yea big time. Excuse me memory. Eh, the one that started XXX, right, she went over in a town in France called XXX.

R: Right

P: Right where they were using the garden

R: That's right

P: And that's what this place was. (cough) It went far away from that trying to get back to

R: Your right, yea the place is lovely

P: Few ideas now

R: Ah it's great craic, it's, it would put a smile on your face and it's great that the lads are getting all that benefit

P: Yea

P: Getting the benefit from it but getting the recognition for it

R: Right, that's important isn't it

P: That's important

R: Doing their work

P: Go past the flowers the carers saying 'oh your flowers, your flowers are doing well'.

That's the ideal part about it. Right, not saying the flowers look well, saying

R: Your

P: Your flowers look well

R: Yea, yea it's really nice. Well, we'll wrap it up on that nice thought. Thank you so much.

Thanks again and [the occupational therapist] will be delighted to know that her input is appreciated. D'ya know because that's what it's all about isn't it getting the lads involved in things that matter and having that sense

P: Oh, she knows.

R: Thank you.

Transcript Three

R: So, the fun and games. Basically, what we really want to know is what's in your head when you're working. How you think about the lads, how you kind of prepare yourself for supporting them.

P: Right.

R: And, eh I suppose the easy way, I've kind of learned, the easy way to ask people is when you start coming to work what would you be thinking about so that you're ready?

P: Right.

R: Because it isn't just turning up to the office?

P: Yeah.

R: Yeah. So, what would you be thinking about when you're coming in to work to get yourself ready for the day?

P: Ehm, well really preparing for work starts the day before

R: Really?

P: Because we do 24-hour shifts. So, eh I really like depending on where I'm sleeping, if I'm staying in mine or if I'm staying in my girlfriends, I have to get ready

R: Pack a bag

P: You know, a day before an actual shift.

R: Yeah.

P: Cause, eh I'm doing a, doing the 13 hours in a day itself is a, like quite a large chunk of work in one day.

R: Yeah.

P: And then you're going to sleep in work, you're waking up in work. You're continuing to work for two, maybe three hours if something goes wrong.

R: Right.

P: So, really. What I'm thinking about is what's the weather like for the cycle.

R: Yeah!

P: And, hopefully not forgetting my keys because most of the doors are locked in the house I work in.

R: OK.

P: And, eh I so it starts with the logistics of getting in and making sure I have got you know a change of socks you know to get through the day. It really starts with the logistics of work, before I even start thinking about the lads. Ehm, really the first time I start thinking about what form the lads are in, is when I come in and the handover takes place

at 10 o'clock. Until then, there's no point in having any preconceptions, because somebody may have had a bad day when you were in the day before.

R: Yeah.

P: And they may be in flying form the next day. So, there's really an onus not to bring any, you know, yesterdays negative to tomorrow's shift. So, you know, I learned in the first place where I was ever working in a day service in XXX, that you just start each day with a completely clean sheet.

R: That's a lovely way to go at it, isn't it?

P: Yeah.

R: Yeah.

P: And the rationale, it really came from one of the biggest crisis situations I faced when I was there, and it was a, it was a service wide crisis because the service user in question thrashed call centre computers and went around head office and it was a huge thing. And, there was lots, there was, thankfully there weren't any third parties hurt, but the service user himself was self-injuring and there was lots of destruction and ehm, lots of blood. It was really emotive, a really highly charged situation. And, at the end of the day, one of the biggest days of this upheaval, our co-ordinator was like brilliant in his training and the way he, the way he communicated with the lads. He made sure that everybody was on the same page, and that everybody approached him the same way the following morning as if yesterday hadn't happened.

R: Really!

P: And we were approaching this day as a new beginning.

R: Wow.

P: And I've taken that with me ever since

R: Wow

P: Because anything can happen on a shift.

R: Yeah

P: And there's no way for me to really get inside a service user's head. There's no ehm,

R: That, that's right yeah. Yeah.

P: There's no way, I can understand from my point of view, and I can try and understand from their point of view, but I'll never understand completely what's going through their head. They'll never be able to communicate everything that gives them anxiety, or just plain pisses them off.

R: Yeah.

P: You know. So, and dealing with five individuals is hard, who are often locked away from their own kitchen because of one service user. You know, you don't know what kind of frustrations are going on, and they didn't choose each other as housemates, you know. They were kind of put together and hopefully they won't kill each other, kind of thing. That's generally how it is in these places. So, ehm, you know, I think you have to come in and give all the guys the benefit of a clean slate each day. Or, even each, you know, not necessarily each hour because you do take their moods as they carry on. But, in terms of individual, kinda, individual episodes of behaviour, there's no point in reading into the next day what might happen.

R: Hmm.

P: When, it could have been as simple as, you know, you or me just being annoyed at something and having a bit of a rant to somebody and that's our vent.

R: Hmm.

P: Often, they vent physically and that's it.

R: Yeah. Done.

P: And, to dwell on it isn't something that helps I find.

R: So, you are in this house, with these five people, who didn't choose to be there, and you are starting with your clean slate.

P: Yeah.

R: Right. So, then, when you're settled in and you've had your handover, ehm, what are the sort of the expectations then. What are you meant to be doing with the day? In terms of how are you meant to be getting on with things, supporting the lads?

P: Eh, none of the lads go to a day service, for various reasons.

R: So, they'll be there all day?

P: They've all been, in, in day services.

R: Are they older?

P: They're all, ehm, late thirties to forty-five.

R: Hmm. Not that old.

P: No.

R: No.

P: So, they're eh they're old enough to be settled and for hormones to not be an issue.

R: Yeah.

P: And they're young enough to do almost everything

R: Stuff, yeah.

P: Have energy and

R: Yeah.

P: So, they really are at a great age for themselves.

R: Yeah.

P: In terms of, getting to know themselves, getting to know their disability and their, some of their limitations and some of how they adapt to those limitations and you know be more accepting of it. You find younger service users are angrier as they come to terms with it, not all but some. One of ours in particular would be like that. And now, even though he has issues with depression, he is quite happy most of the time. So, I'm rambling a bit now.

R: No, no I'm getting a feeling now. So, these are five people

P: Yeah

R: Living together, and are there two staff on?

P: Two staff on the overnight, and for the last few months we've got three staff on, for four of the days.

R: OK. And, that's three of the days there's only two.

P: Yeah. Ehm, sometimes we may have extra staff on, but usually not.

R: Yeah.

P: Ehm, in the couple of years I've worked there it's been generally two staff, twenty-four hours right through. And, it was accepted that we were understaffed. So, there may even be a drive to get more staff hours.

R: So, it's challenging?

P: Very.

R: And they are a particular kind of person?

P: Eh, what's?

R: The lads, in that would they be particularly challenging?

P: Yes and No.

R: If they're not going to day centres?

P: Yes and no. In certain situations, they can be very challenging. And, when you get to know them, you get to work with what mood they're in, you get to accept that every so often, a few plates will get broken,

R: OK.

P: It's a matter of communication. And, your approach to that really dictates how stressful it is for you.

R: Really?

P: So, I'll approach somebody smashing stuff in a café as, OK, immediately we get out, make sure everyone's safe. But, it's a form of communication. Sometimes it's for an underlying reason, sometimes it's just purely impatience because they're waiting for somebody, another service user to do something. And, so, often, five different people sharing the same staff becomes a conflict of, I wanna do this, I wanna do this. The fastest way out of a café is to start smashing it up. And that's the simple communication.

R: Yeah. Yeah no I can see it.

P: So, it can be challenging, and ehm, I'm told it's one of the toughest places to work in [this service]. In terms of the day service I started off in, it's a doddle.

R: Yeah. Really?

P: Yeah.

R: OK! (Laughing). I've been to, I've met some of the people in XXX right?

P: OK.

R: And they're like, amazing, fantastic whatever. And, I would have known other people in special schools who were very challenging.

P: Right.

R: And, [this service] has everybody, in between, haven't they like?

P: Right.

R: The range of ability is amazing.

P: Ok. The service I was originally employed by in XXX, was a high needs disability service.

R: Right.

P: That was set up because there was nowhere for five or six service users of different families. And, they set it up, together.

R: Oh.

P: Just for their own kids.

R: Right right.

P: Because nowhere would take them.

R: Right.

P: And, they grew on the basis that they would take anyone, for any reason.

R: Really.

P: So, they had everybody, from blind, and deaf, and you know in a wheelchair with very limited ability to do anything, to quite high functioning people with autism, who just had the potential to be quite destructive when they were feeling confused, and very muddled. So, every, like, people were very high functioning and could really speak about their feelings when they weren't in the thick of, you know, a temper

R: Their being overcome, like,

P: To people who couldn't speak, couldn't see, couldn't hear. And everyone in between.

R: Wow.

P: All kinds of learning disabilities.

R: So, you have a lot of background, you have a lot of experience.

P: Eh, in a short time I got quite a lot of experience. Yeah.

R: And how long would you be here now in [this service]?

P: Ehm, over two years.

R: Yeah. And how long were you in XXX?

P: Eh, I was there six months, and then XXX in various day centres for six months.

R: Ok. Right, so you have quite a bit of experience behind you.

P: Ehm

R: Yeah.

P: In a manner of speaking. Yeah.

R: Yeah.

P: I suppose at this stage yeah.

R: So, would there be particular people or particular ways that you support, say, you're getting through the day, and you want to support someone say in their social skills, or in their personal care, or in their communication? What would you be thinking about and how do you do it? Is there any particular person in mind you wanted to use just as example to help you explain, or would you have a general approach to how? So, you're tuning in, what I'm hearing is that you have to keep tuning in.

P: Yeah. There can't be a general approach, because one service user is XXX, one person can speak and articulate what [they] want, one can speak but won't generally speak much, because he finds it difficult to physically speak. Ehm, and one has four words that I know about, including hi and bye.

R: Ok, not much left there.

P: And ehm, another service user speaks a lot but much of it is echolalia, and he will often say, yes when he means no.

R: Oh. Dear.

P: And, sometimes, he'll repeat what you say, so you have to be careful not to ask leading questions, or if you did, when you see him becoming confused, you have to, instead of listening for the word he says, you have to listen to how he says it.

R: Ok.

P: For example, I was on the bus earlier on, and he became, he said he didn't want to go out. And he, always wants to go out. As most of the guys do. And ehm, but he was saying no, and I was like, ok, this is unusual. So, I just pulled over, and I just said the word 'drive', and then he went 'drive'. And he felt relieved. I could hear the relief in his voice, he said 'drive', so I was like Ok, he isn't asking to go back, he just heard what I said and repeated it back.

R: Oh my god.

P: So

R: Wow.

P: Yeah.

R: So, this is very complicated.

P: Yes and no, may not mean yes and no.

R: So how do you communicate?

P: Ehm, well in that instance, it was, it was trying to see if the normal prompt for him to go out, ehm, lead to an anxious reply or a relaxed reply. And it was visibly more relaxed.

Ehm, one of the service users when we're out, he doesn't like demands being made of him, so I'll tell him what I think he wants to order, I'll say I'm going to order this, and if he doesn't give me any response I know it's ok.

R: Yeah.

P: But, sometimes he might shake his head if he strongly doesn't want something. And, at that point I have to very quickly go, ok this. And, he'll relax and that's ok. Ehm, otherwise he might get caught up, and he gets into physical loops and mental loops. Ehm, he was stuck XXXX, nobody could talk him out of it.

R: My goodness.

P: So, could imagine what psychological state anyone would be in to be stuck XXXX, let alone somebody who can't speak. So, when you're communicating, you're looking for emotion.

R: Yeah.

P: Because you're trying to read how somebody's feeling <yeah>, and even the people who are verbal, and can communicate well, and have. You know, even those people, sometimes may be lead into saying something. So, you have to be very careful about how you phrase a question.

R: Right. So, basically you probably don't talk a lot then?

P: There is a lot of talking people through things, and redirecting people from, say XXX. So, sometimes I do talk a lot and sometimes I don't.

R: Yeah.

P: It's a mix. There's really, ehm, there's no standard hour per day. Ehm, there are standard patterns of what we do, I'll often go out with a couple of the lads, go for a walk, where there's not a lot of distractions, a beach, or yeah somewhere in a park where there aren't you know lots of cafés or shops where a service user might XXX.

R: Hmm.

P: Ehm, so there are patterns of what we do to get the guys out of the house and help them feel more relaxed and there are clinical plans around some of it so that they use up energy and sleep better so they're not like relying on medication for sleep.

R: So, you'd be looking at the routine to keep people sorted, to some degree? And, you have to kind of be thinking of getting through that routine with them, that's going to help them be relaxed.

P: Yeah.

R: And then, would you be going places every day then?

P: Yeah. Most of the guys would get out every day.

R: Yeah.

P: Ehm, sometimes somebody might not want to go out for a few days.

R: Yeah.

P: And that's their choice, if they don't want to go out they don't have to. Ehm, it's up to us to support what they want to do.

R: So, that's interesting cause, would you have things like ehm, an individualised plan, or any of those things, those personal support plans?

P: Yeah.

R: So, that would be there for each person?

P: Yeah.

R: And how do you figure out the goals? Like, how do people figure out goals?

P: Ehm, the only time I've actually actively been involved with doing it was in previous jobs, where I would either sit down with somebody, or I would invite them to do exercise therapy or music therapy, based on what they started becoming interested in.

R: Yeah.

P: Would help them develop what they'd either shown they had been interested in by their behaviour

R: Yeah

P: Or, if possible, they can ask. And,

R: Yeah. Yeah. So, that brings me into the one now looking at people's hobbies and interests, so you were just saying how you'd offer experiences and then see what people like?

P: Yeah.

R: And, would that be the same with these lads now?

P: Yeah. I'd try that as much as possible. And, I said that we had a staffing, kinda issue, in that we were very thinly spread.

R: Yeah just the two of you.

P: And ehm, it means that as there's more paperwork to do since HIQA came in, that there's less and less time to actually do what the guys want to do, and what might help them feel more fulfilled, or, what I personally like doing is helping a service user surprise themselves.

R: Really?

P: Yeah, and

R: Like?

P: The biggest ehm, kick I can get in the job is when somebody does something they thought was impossible.

R: Really?

P: That they'd excluded. You know, like, you or I might like to go to the moon, but we don't think it'll ever happen.

R: Yeah.

P: But, Elon Musk could come in and say 'here I'm taking you to the moon'.

R: Yeah. Yeah.

P: It is actually possible. It's just very very unlikely.

R: Very unlikely, yeah.

P: So, we say it's impossible.

R: Yeah.

P: But, probably quite rightly.

R: Yeah.

P: And, that's the way I think about it for some people, like ehm, I brought a service user in a wheelchair rock-climbing before.

R: How did you do that?

P: Ehm, well we hoisted her up on a flat bed, that rock-climbers would use to sleep on a rock face.

R: Yeah!

P: So, we helped her into the, into the bed. It's a flat frame with springs so it's like a bed. And ehm, we then hoisted her up, because we had mechanism and she could hold the wall beside her, and she was so excited she was hyperventilating.

R: Oh stop.

P: And, I never, I never, at the time I didn't think about the significance of helping somebody rock climb. Because some people were scared and we had ladders set up that some of the guys would pluck up the courage and go up a few steps on the ladder that was going up the rock-climbing wall. All harnessed in obviously. But, ehm, when she came down she was nearly crying and she said 'I never thought I'd be able to do that'.

R: Wow.

P: That was, it was a real eye opener, and ehm

R: Yeah.

P: And, you know.

R: That took an awful lot of planning.

P: I think, ehm, the planning that went into that particular service user doing it, was a lot of planning that wasn't specifically for her. It was just that the day service was bringing between ten and twenty people every week to go to that rock climbing, and she came that day. So, there was a lot of work but not specifically for that one service user. And, it was, it was a lot of work but also a lot of fortune that she wanted to go, she was active, she was up for getting out of her wheelchair, and you know allowing us to hoist her up, because it was,

R: Hmm, very scary, could have been?

P: Most people wouldn't go up the ladder. So, for her to place that trust in us, was, that was probably one of the biggest parts of it. That was a lot more work than anyone else put in.

R: Yeah.

P: Ehm, so, those kind of things, I don't get a chance to do so much anymore.

R: Hmm.

P: And for that reason, I do want to move into more day service stuff.

R: Yes.

P: Because I do recognise that people need to be able to relax in their home,

R: True, yeah.

P: And it is good to have, that split between a place to relax and a place to push yourself and surprise yourself.

R: Hmm.

P: So, I'm caught in this kind of, I have been very happy there, because we do go out a lot and I was working to help the guys do new things and bring them new places. Ehm, but it is still their home, and it's still, you know, they still need to be able to come back and just sit on the couch and be able to do nothing.

R: Hmm.

P: Ehm, so I think it works better for me, not necessarily working with the service user, but for me, eh myself, professionally, if I'm in the zone where, 'this is what we're doing now'.

R: Yep.

P: We are here, to surprise ourselves, we're here to do some exercise therapy, for the next hour.

R: Yeah.

P: Ehm, when I was in XXX, two of the biggest fans of playing football were two old ladies in their wheelchairs.

R: Seriously. Really?

P: And they were also two of the best boxers!

R: Go way!

P: Yeah! Stuff you would never know

R: No.

P: Unless there was some equipment lying around

R: Wow, that's wonderful

P: Or, our manager says 'you go out in that field and just do something'.

R: Yeah.

P: Invite whoever wants to go out there, to go out.

R: Yeah. Yeah.

P: And, that's the beauty I suppose of having forty or fifty people at the start of a day and you're able to go, 'who wants to do this?'.

R: Yeah. There's energy.

P: Yeah.

R: Yeah and people give you ideas

P: And there's unexpected energy

R: Yeah, yeah, yeah.

P: People you don't expect to want to do it

R: Yeah.

P: Can end up loving it the most

R: So, for people to get engaged, it's good to have other people around?

P: Yeah.

R: I can see then with people, with five who live with each other all the time, that that's not the same energy source at all. As if, you were going to a day centre where there's different people coming, and yeah?

P: Yeah. There's a lot of ehm, obviously there's a lot of eh, negative energy between people as well.

R: Being with each other, yeah.

P: In a hub atmosphere, with forty or fifty people

R: Yeah

P: Lots of them have, you know learning disabilities, or ehm, have autism, that kind of thing. So, it wasn't all plain sailing. Eh, but yeah in the home atmosphere you build up those kind of patterns, hierarchy's, kinda

R: Yeah, you do.

P: Eh, who takes what food off what person, that kind of thing.

R: Yeah, sits on what chair, and

P: Yeah.

R: Yeah. So, back to the hobbies and interests, and how you support people. So, you've given me ideas there that you, you try and do something every day.

P: Yeah.

R: And, ehm, you tune in and see what people like and don't like. And then you mentioned HIQA. So, is there a lot involved in that?

P: There is a lot of paperwork.

R: Ok.

P: And, I suppose it's not all HIQA. But a lot of it is HIQA requirements and there is more paperwork to do since I started, which was shortly before,

R: And why do you have to do that, yeah?

P: Well everyone has to document what they're doing.

R: But, really? All day every day, sort of?

P: It isn't a case of having, ehm, paper with you at all times ticking it, but there are huge amounts of paperwork to do, there's lots of safeguards in terms of ehm, documenting people's behaviour. So, if we're you know, it can be anything to monitoring somebody's, ehm their mood if they're on mood stabilizers, to, it could be monitoring somebody's bowel movements.

R: Hmm.

P: It could be, just lots and lots of things

R: To be recorded

P: Need to be recorded. Every time you go out you have to count,

R: The people?

P: All the money before you leave

R: Oh?

P: So, you have to make sure the purse is correct. So, you might be counting, depending on how much money is in a purse, a couple of thousand euro, for taking three people out. Ehm, you're not taking that amount out, but you're, you're counting what's in the safe for each person, and the staff expenses and putting that back

R: Oh gosh

P: And just taking what you're taking.

R: Yeah yeah yeah.

P: You're going out to the bus and then you're doing checklists to see if there's oil leaks, and windscreen wipers

R: Are you serious?

P: Then you're writing out where you're going, what time it is, the mileage on the bus, you might have to go to the petrol station then.

R: Yeah

P: And you might have to, you know, you go and you know fill in extra stuff because we have a fuel card, you give the guys there the mileage, and then you do write about the guy's days, what they're doing. Ehm, when you come, like, all the, like, we're considered food workers.

R: Ok?

P: So, our HACCP training means that you know, we're legally liable if anybody has food poisoning.

R: Ok.

P: So, we have to probe the food the same as a chef would.

R: Are you serious?

P: Yeah, totally.

R: And record the temperature that the sausage roll is at?

P: Yeah, it's got to be 76 degrees or over when you're cooking food. Ehm, you laugh at that, and I did

R: I'm laughing.

P: when I started

R: Yeah, you have to do it.

P: But, about XXX I came in from a couple of hours out, and I had, somebody was relatively new who doesn't work where I work normally.

R: Yeah.

P: And, I was asking how she was getting on with the dinner, I'd asked her to start, which was just fish and chips.

R: Hmm.

P: In the oven.

R: In the oven.

P: Yeah and she asked me if I could serve it up, so I was like ok, and I probed it and the fish was 45 degrees. And I was like, how long has this been on? Did you turn it off? And, eventually we figured out that she had three trays of things in one oven, with the top grill on.

R: Yeah. Oh no, not the oven.

P: Not the oven. So, it wasn't cooked. Ehm, so you want to presume everybody knows how to cook a piece of fish. But they don't.

R: They don't.

P: And that's where all these regulations happen

R: That's why you have to do your HIQA.

P: Because one in a million. So that's, you know, we're food safety workers, we're professional drivers, we're, like we're, medication, like ehm

R: So, you do the meds as well you see, yeah

P: We do the meds, so obviously that's

R: And you do your training for that, and your protocols

P: And that's very strict that that's documented properly. And, if you have to administer any PRN's, so any once off medications. You've got to make sure you're adhering to protocols. So, it's not just writing you have to read to make sure you be doing things right

R: Right

P: because there's so much there like,

R: Yeah there is!

P: You can't know it all.

R: Yeah. Yeah yeah yeah.

P: It is there so that you can refer to it.

R: Ok, so that's a lot of extra thinking and time

P: Oh, it's a huge amount, yeah. I mean in the two years I've been here it's changed a lot. So, I can't imagine what it was like ten or twenty years ago. The people say, you know, the job has changed, because it's a job now.

R: Yeah.

P: It's not a case of showing up and looking after the lads and bringing them off for the day

R: And having a good day out

P: And coming back after seven. Yeah.

R: Yeah

P: And, lots of it is to the detriment to the guys service

R: Yeah

P: Unfortunately.

R: Yeah, because you have to keep stopping and doing these procedures

P: Yeah

R: And somebody has to be hanging around waiting while you do that.

P: Yeah.

R: And you lose the kind of flow.

P: Yeah. And, the nature of organisations is that they're risk averse.

R: That's it.

P: And, safeguarding policies are that you have to allow people to take risks, because that's a part of life. It's actually written, that people need to be allowed take due risks.

R: Yeah

P: But, an organisation doesn't want to take any risks with somebody's safety. So, you find people are actually trying to make somebody safe and they're contradicting a safeguarding policy, by adhering to a certain part of it too much.

R: Hmm.

P: So, we have policies that contradict each other all over the place.

R: Really

P: And, yeah. It's such a balancing act.

R: Yeah.

P: It's like trying to live life for somebody else. If you're doing it for one person, you have some chance of doing it pretty well. If you're doing it for five people, and there's ten or twelve people doing it, it's complicated.

R: Yeah. That's very confusing.

P: There has to be, there has to be a lot of paperwork, so that people can pick up what's going on, if two people call in sick.

R: Right, yeah.

P: Because that can happen. That happened in another house last week, two people called in sick.

R: And they needed to have relief staff who knew or didn't know the lads then?

P: Well, ideally, your paperwork, if two people who had never met the guys came in, the paperwork would be able to get you through the day.

R: Hmm.

P: It might not be a great day for the guys, but they should be able to get through it.

R: Hmm. Yeah. So, you can see a value in all of that?

P: Yeah. We just need about twelve more people for it.

R: But you need the staff so you can do that other?

P: Yeah.

R: Yeah.

P: That's it.

R: So, it's again, back to this idea of supporting people to do what they do, and supporting them with their goals, and it seems to be it's to do with how you know them? How well you know people.

P: Largely, yeah. Say one of our service users for a while was going to dog's trust, to walk some dogs. And that was because he mentions his dogs name every so often and does appear to enjoy it. So, his keyworker decided this might be a nice thing for him to do, because he likes to go out and go for walks anyway, so why not walk a dog. So, you're trying to think creatively for service users.

R: Hmm.

P: I found out that one of the guys wanted to go to a museum, when normally people, he likes cartoons, he likes ehm, bright colours and things that are very childish in imagery. But he also likes going to museums and he wants to you know, he likes things that are more adult as well. It's a bit, there can be a tendency to infantilise people a little bit?

R: Hmm.

P: And, I think it's, you know, I think it is an easy thing to do, you know especially for parents, because they're looking after them and they get to know them so well. So, eh I think traditionally it has been a kinda, a sector that service users do get kinda treated you know a bit more like children. Obviously, they have, you know because it's written up

that they shouldn't be any more. It wouldn't be written up if it wasn't something that happens, you know.

R: Ok? But then, how do you know how a person is able to be an adult? Like, that means taking consequences, doesn't it?

P: Not necessarily. I mean, we're not asking our like, nobody is asking them to take responsibilities that they can't take.

R: Ahaw.

P: But to, address them as an adult.

R: Hmm.

P: Ehm, if somebody wants to be called 'a good boy', you know, remind them that they are a man. It's like, 'yep, you're a good man'. That kinda thing?

R: Yeah.

P: Ehm, cause you end up with people in their fifties or sixties being called 'awe good girl'.

R: Yeah

P: And, maybe some people like that and that's reassuring for them, but a lot of people who have had breakthroughs in their communication, have come out and said that this has been a negative thing

R: Really?

P: And they feel like they should be treated as a normal human being.

R: Hmm.

P: So, I think wherever there's ambiguity, I always feel that I go with the treat them like a normal adult. And, if there's a, you know, if that person displays any like desire to be treated in other ways, that's fine.

R: Ok.

P: We all want to be treated in certain ways by our friends,

R: Hmm that's true

P: family. And there's nothing wrong with that. But when we're out and about we expect to be treated like adults.

R: We do. Yeah, yeah.

P: And, you know, people with autism are normal people, they just happen to have autism. (Unintelligible) the same.

R: Right, but yours sound really interesting. And it's so, again it's how do you even know how a person interprets responsibility? So, how do you get an idea of what a person can handle? So, people make choices,

P: I guess that's built up over their life, I think

R: Yeah. And for you to know what a person's capable of, yeah.

P: Yeah, and, I guess by helping them push their boundaries as well. That's one of the things I was tasked with doing in XXX and something I've brought to my other job here as well.

R: Yeah, yeah.

P: Ehm, so not being afraid to bring the guys on the cliff walk around [the coast].

R: Oh my god. I'm terrified already. (Laughing).

P: Just because there are cliffs around there, I mean it's not a sheer edge where if somebody falls they're in the sea.

R: Well, they might be just, nearly in the sea.

P: Nearly. But if you walk down the footpath it's more dangerous.

R: Do you think?

P: Because cars are a lot more dangerous than,

R: That's true, that's true

P: than stumbling over into some (unintelligible).

R: So, you've gone on that cliff walk?

P: Several times yeah. You look scared?

R: I just did a bit of it, yeah, I'm not great with the old heights. (Laughing). And your lads went?

P: Yeah, and there are ones that I wouldn't take. And there's one guy who I thought would like it, and when we got to the steps, he just, you could tell he wasn't into it so we turned back.

R: Ok.

P: So, that, like, helping people to kind of push their boundaries, then you find out what they do like and what they don't like.

R: Yeah, and you wouldn't know until you try.

P: Yeah.

R: Yeah. And that's again the tuning in, which is what you seem to be really good at. Like how did you know he didn't want to go any further, did he say that's it I'm going, or?

P: Ehm, I think that, he was looking at the steps. He had gone through a few and he had stopped and looked at them, and I asked him are we going to turn back now? And he turned back.

R: Yeah.

P: Ehm, and actually that was the second time I asked him. The first time he kept walking, now that I remember it. It's a good while ago now.

R: Yeah. Well, that's really tuned in of you. So, you didn't really have an agenda, you're guna do this, you're guna feel great if you do.

P: Oh, no.

R: No.

P: And if I, I think that somebody might enjoy it. I might say, awh you might enjoy that. And that same person, ehm, when I got him a dinner in [a restaurant] one day, there was some ehm, some artisan black pudding along with the scallops.

R: Oh yes. Yeah.

P: And, he doesn't like black pudding, but when he ate everything else and he left those, I said 'that black pudding is probably a little bit better than the black pudding you taste on a Sunday morning, you should give it a go if you want'. And sure enough he ate it.

R: Hmm.

P: The suggestion was enough, to help him see that

R: See this is the subtlety. And, it's I think what I'm hearing is, is the being able to say no, or he can indicate no and you don't have a big agenda about the pushing, you know he's, this is as far as he's gone.

P: Yeah.

R: And that's the big piece you recognise. You recognise when he says no that that means no.

P: Yeah.

R: Yeah. Even though you get your buzz from him doing stuff, it's actually the fact he says,

P: Or, I might even go, maybe next time.

R: Yeah.

P: And leave it open. But not leave it as a well we've closed a door there, but.

R: Wow, wow, wow.

P: That you're not closing doors as you're going back and forth

R: So, he'll come back. He'll think 'I can come back, there is a next time'.

P: Yeah.

R: That's really subtle.

P: It has to be.

R: It's really subtle, but it's very powerful

P: It has to be. It has to be so subtle. There's some people that, if you say their name, certain staff if they say their name they won't do something for them. Just by saying their name.

R: Oh, my goodness.

P: Yeah so you really have to get to know very subtle things about someone. And, they interact with each staff member differently. So, what works for one person is not going to work for everyone else. Or, maybe anyone else.

R: Yeah. So, it's really fascinating, because what we wanted to know, you see what we're getting is the story of how people support people to do stuff, but it's all this anticipation and the tuning in. And, and as you say, it's relational.

P: Yeah, it's.

R: It's all this knowing and then trying. But you, you seem to be able to, you look for, you give options, and then people choose the options, and then you respect that. And then, as you say, well that's for today, and then tomorrow we might have,

P: Yeah.

R: Yeah.

P: Hearing your feedback on it, it's, it's almost like you are an extra part of their brain, not an extra body there.

R: Yeah, yeah.

P: And you're just trying to like help them in a certain direction

R: Yeah

P: Help them make a decision, where if they were just there, they might be overwhelmed by trees, leaves, just you know

R: Yeah, yeah.

P: Like, sensory kinda wise, that's enough to distract them. But, you can help them through whatever path it is, or

R: Yeah, yeah, and yeah. And, it is so subtle, but it's also, although it is you as a separate person getting a buzz from them doing stuff, you're still getting the buzz from them saying no.

P: Yeah.

R: Like that's still really good for you.

P: Or you might be disappointed, but you might go, fair enough.

R: Yeah. It's, see that's so difficult to manage, because as you say, you're part of their brain, and then you are yourself.

P: Yeah.

R: And you have your own expectation and you have to accept that.

P: And you do want things for people.

R: You do.

P: And you do want them to develop, but they want to develop in their own way.

R: In their own way. And it's you all the time giving the space for that choice.

P: Yeah

R: And as you say, clean slate every day which means you haven't closed the door.

P: Yeah.

R: So, so subtle.

P: And sometimes, sometimes, you might ehm, find that even though they don't choose the option you would hope they'd choose,

R: Yeah

P: That another option you didn't even see yourself, is actually even better.

R: Imagine.

P: Yeah. Ehm, we had a drum circle in XXX when I was there, and eh, I'm a musician so,

R: Oh, are ya,

P: So, I was helping the music therapist on site, to facilitate, to lead that each week, because she was only there three days a week, and I was there five days a week. And, through just constantly having it there, between where people arrived in in the morning, and the main hub where people were lead to and would congregate before they went for their different activities, be it out in the community or on site. And, we would set up the drums and the shakers and everything else, about twenty or thirty seats and have some staff around playing drums and helping people to play drums, and it built up. And everybody who did decide to get involved, which was most people, ehm did in totally unique ways, and some very typical, and lots of them absolutely loved it. There was a very, the very incredibly strong case for music and for letting people do things at their own pace,

R: Yep.

P: Ehm, there was a service user who with Down Syndrome, had a severe learning disability, was in fifties, very old for someone with downs syndrome.

R: Hmm. Very old yeah

P: And when she went into that day service at first, she used to stay in a toilet cubicle with either a football, or a dolls head in her hand. And she would just shake it and

R: Ah, right

P: She would spend all day there.

R: Yeah.

P: And eventually, this was before I ever started working there, eventually we coaxed her out by setting up a key board in the corner away from everybody else

R: Really

P: And she would just sit there, hitting the keys, and it wasn't music, but that musical feedback for her is what she wanted.

R: Yeah

P: And, she was ok there as long as nobody disturbed her

R: Yeah

P: And she was in her own space. And then, because we knew she was musical, we wanted her to partake in the drum circle. And shortly after we started there, ehm, I had the idea to just leave a seat, out, about maybe 6 feet away from the group, that was just there by itself, with a drum. And, she would normally just pass by, and every so often then she started sitting down, at that seat away from everybody and hitting it. So, we knew that she did want to participate and she liked it, so we started moving the seat, slowly, slowly, slowly. And ehm, some days she would sit down, and some days she wouldn't. And one day, we just forgot to put out a seat and she just sat down in the circle.

R: She didn't.

P: And we were like, (laughing), we were like wow, it happened.

R: Yeah. Yeah.

P: And that was about three months after I started, and about two months later, she sat down, and one of the guys who was ehm, I think he was down syndrome as well, like, ehm, very limited vocabulary, one of the mildest mannered people I've ever seen in my life. He would just, he'd sit there at a table, not saying anything, not doing anything if nobody said anything to him. Just, he'd have an odd look around, 'do you want to eat your lunch', in front of him, 'ok'. And ehm, he sat down beside her, and he moved his chair closer to her, and looked over, and she gave him this big look. Like, her chair, the metal of his chair was there,

R: Right

P: Right beside hers.

R: Right

P: She looked over, looked at him for about five seconds, and normally, this is where she would just get up and go.

R: Yeah.

P: And she just looked at him, and looked back, and started playing her drum. This was the first time this guy had ever displayed any sign of direction.

R: Yeah yeah yeah.

P: that I had seen.

R: He actually got up and put his, yeah

P: He like, pulled his chair forward, he would normally, he would have to be told where to sit or to sit down, or something. He wanted to sit beside her. And then she didn't mind him sitting there. So, when I saw that I was like ok I want them to share a drum at some point. So, we used to set up two seats

R: Stop!

P: And kind of leave together in the hopes, and they started sitting beside each other, and then eventually one day, the drum there between them, they were both hitting it.

R: Imagine that.

P: And the biggest outcome for me was not any of the musical development. Some of the people started, you know, coming you know quite good with the shakers or having great fun with the drums. But it was the social development, and people with disabilities often don't see any social value in other people with disabilities because they can't get them their food, their drink, their rewards

R: You're right they're not good servants, yeah

P: So, they don't, they don't see the social value that, of the interactions

R: The companions yeah

P: Whereas it started happening naturally in the music circle. So, it was like a form of occupational therapy, because the occupation,

R: Absolutely. It's beautiful though.

P: The occupation was, making noise, whether it was rhythmic or not, it was just 'make some noise, go on'. And then the people started viewing each other with that, eh

R: Yeah. Beautiful

P: You know, as humans.

R: Yeah, that's amazing connection.

P: It was. It was incredible.

R: Well, that kinda says then, all that tuning in, and all that being aware is really the fundamental thing. It seems to be how you do your work.

P: Yeah, always being open to, the service user's opinion, treating them with the same respect you would want if you were in that position.

R: Yeah.

P: And

R: And yet having the possibilities, having the open mind. It's amazing. Well, that actually answers, because what we're really interested in is the thinking around the people and how you get people involved in stuff. And that's it, it's the subtlety, it's the tuning in.

P: Yeah

R: Yeah, you can't really train that it's just amazing

P: Trying to just see what people like, and then facilitate them doing it again, or facilitate them doing something similar if you think they might, they like, you know, they like walking on the pier in XXX. We'll make it then for like, to go in a sailing boat. You know, just.

R: Thinking it, adding the bit on. Yeah, it's very creative. XXX

P: But even people who are not musicians,

R: Think like that

P: Yeah. You try to develop.

R: I dunno. I've been talking to people here and what it is it's the tuning in and they're all different. Like, the people in the garden, it's the tuning in again, it's amazing. And then you put HIQA with that, and just it's very different mindset.

P: Very different. Yeah, it's, it's like introducing a hospital blueprint on top of something that already exists. So, it's like, here's what you built, let's give you our foundations, and put them on top

R: Hmm, on top is right

P: And then we try and like build underneath their foundations, and

R: Yeah, yeah

P: It's murky.

R: Isn't it.

P: Ehm, I do see the value in it. But I also, ehm, I also see it taking away from the guys service, as well.

R: Yeah. When the skills needed, as you say, what you've been doing, it's so skilful, it's like HIQA will never capture that people are tuned in to people.

P: No. it's like self-driving cars. When are we gonna have them they can do a bit of it. But, but you can still trap them in a circle by bending a circle of white. And then they can't leave because it's a continuous white line.

R: (Laughing). Oh my god, yeah yeah yeah. That's a bad thought.

P: So, there's certain things, and abuses that HIQA is safeguarding against. Which is great. But, then, it's curtailing that freedom for them to be, well maybe not in all circumstances, but I see in my,

R: In a setting like this people are so unique

P: In my microcosm, maybe I'm a bit down on HIQA because of my own personal circumstances, maybe it's not an organisation wide thing.

R: Well

P: But I do, I don't hear too much positivity about them.

R: No, no. Because the people are so different here.

P: Yeah.

R: Yeah

P: That's often the way with new things. I have to say, we're streets behind XXXX in terms of how we provide a service, and

R: Attitudes?

P: Attitudes, and also just how professional a service is.

R: Yeah.

P: Maybe HIQA is not the right governing body for a disability service at all.

R: I don't think it is.

P: And, fingers crossed they'll realise that and it'll go specifically to disability

R: Hmm. But see, if you start looking at a disability perspective around rights and all of that craic, it's a very different view, to what HIQA would have. So, they're safeguarding as you say, and their, all their attitudes about procedures are coming from a different mindset about people with disabilities.

P: Definitely. Yeah.

R: Whereas, Australia would be into people's rights and I think their mental health is very good as well isn't it? It's a different view.

P: Yeah, and they're continually changing. The same as Ireland, I think all health services are continually changing, but XXX [it is] starting to go towards service users could allocate their money individually, per hour.

R: Yeah.

P: Rather than going, you know. For example, 'your [this service], you're looking after me, I'll give you all my money'. Ehm, it will probably go the way it is in Australia, where they go, 'well, I'm sleeping in your house, but when I go out during the day I'm going to spend it on here here and here. I'll have an hour in this leisure centre, I'll have an hour going to a deaf centre, or an autism specific cinema, or whatever it is. But they might, eh, whatever they make up, that will probably be the future.

R: A different funding.

P: Fingers crossed. Not that it's different funding but the service user who has the ability to split it up and budget the way we have to split up our own money. We don't give our, all our money to our landlord or bank, and say,

R: Yeah yeah yeah

P: 'I'm at your mercy now, please treat me well'.

R: Yeah, yeah yeah. Well, listen thanks, that's that. That's the whole piece we're looking for is that subtlety. It's really interesting. And, then for a service, the big picture is if a service is trying to run a service, how do they really nurture what you're talking about.

P: Well, this will probably be great feedback for them, because we don't get a chance to talk this stuff out.

R: Yeah, no you don't get a chance to talk this out. And, yet it's the quality on the ground, experienced by the lads.

P: That's it.

R: And how do you know they have it? You only know they have it if you're part of it, and you see how they're being thought about.

P: Yeah.

R: And how, you do a lot of the thinking about them, so that they can engage, or that they can do stuff or as you say, even the clean slate, is a really nice life to live. If I'm a person and I get very distressed, and then there's actually a clean slate the next day. Well, that gives me a chance too, doesn't it?

P: Yeah

R: It's a lovely attitude.

P: Yeah you don't want some cycle of shame, where

R: No, you don't you feel bad enough don't you

P: service users are waking up going, 'no, I was angry yesterday'.

R: And to hold that yourself as a staff like it's hard to let go. But, to be able to just do it is really healthy. Well, it's healthy for everyone

P: Yeah.

R: But it is actually healthy.

P: Yeah, it is.

R: So, it'll be interesting because we're talking to people from the different services, and then everybody's sort of, day to day life is different, depending where they are. But the thinking, is really all about the tuning in.

P: That's good to hear.

R: Isn't it interesting.

P: Yeah.

R: Everybody does it differently, but it's that. And the likes of HIQA doesn't really help that.

P: No, they don't quantify that. Not yet.

R: No. I don't know how you measure it.

P: Yeah.

R: Yeah. So,

P: Cool.

R: Yeah very cool

P: Thank you very much, that was enjoyable

R: Thank you so much. It was really good to have you.

Transcript Four

R: So, you did get a copy of the questions and really what we're interested in <well now yeah go on but listen>, and we'll go through them again. Now the real thing we're interested in is how you think about when you go to work, it's what's in your mind.

P: Yeah ok.

R: And that's the piece that really is interesting for us, because service users are so different, and settings are different <yeah ok, now> and it's quite a challenge for a service to get their heads around ehm, what are you delivering and what's the person's experience, and then where are staff in all of this?

P: Yeah. I understand.

R: So, what we're talking about then, the basic stuff is, for example like how many years have you been working with people with autism? Just as a kind of a warm up, how many would you be?

P: Approximately five years now. Always with [this service].

R: Oh, always with XXX yeah.

P: I began with XXX as a ehm, do you want this detail?

R: Well, just generally so we have a sense of, you're with the agency for five years.

P: Yeah, so about three, almost four, three and a half years I was relief staff.

R: Yeah

P: And then I got a permanent position.

R: Yeah. And, how many people a day would you be supporting? Would it be a small number or?

P: It's two staff to five people.

R: Oh, right <yeah>, it's intense.

P: Yeah.

R: Yeah, yeah. So, that would be different in other parts of the service it would be different for other people.

P: Hmm, probably yeah.

R: Yeah. So, ehm, when you go to work then, big question is, when you go in, what's in your mind? So, you want to support somebody in their daily life, right. What way would you think about going in for their hobbies or their interests, would that be in your head when you go into work?

P: Well, now, yes but, now you see we have five service users. Ehm, there are two people working with them. That's ok. Yes, the support end of the job <yeah> as in looking after

them, from advocacy <yeah>, to, to their health care, to all between medical and social <yeah>. Eh, some of us are key workers and some of us aren't. I'm a key worker, so do you want me to talk in a key worker's frame of mind <yeah, yeah>, as regards one particular guy, <yeah> or working in the whole environment of the five guys?

R: We'll probably look at both, but being a key worker helps explain how you actually do your work.

P: Ok, yeah well now the five, what we have in, within the team XXX where I work, we have a plan, for each day where we try to accommodate every service user to the best of our resources and abilities. And, so, you asked me what's on your mind when you're going in. What's on your mind is, when I'm going in is ehm, first of all ehm, you're thinking of OK, what day is it today, who's going where <yeah>, who am I working with, because some, a lot of the staff at the moment are, because of circumstances we have a lot of relief staff, and there's a lot of staff who don't drive, so you <ah, yeah>, end up doing a lot of driving. Eh, and so, then you know, 'when will we fit this in with everything else?'

R: That's it.

P: As in the cleaning, yeah the cleaning and the cooking. I mean the cleaning and the cooking and the lists of that end of things, between food preparation, food management, cleaning of the house and everything, can take, it eats into everything. Also, money counting. Little things like that, and writing in the daily reports. There's a lot of, lot of, lot of paperwork involved, which is great in a way but, it's. What's happening is, what is, what feels very, it's not being defeatist but, what you feel at the time like, you can understand all the new progress we're making with all the new systems being brought in, all the new policies and procedures that are being implemented since HIQA have taken over. Eh, but, and and and and there's no question that this is necessary, but on the other hand, what can be happening is that you're not getting enough time to do the other part of your care work, as in, interacting and supporting the guys.

R: Yeah.

P: So, what's on your mind when you're walking in well it's 'I hope I get a good run with somebody today'.

R: Yes, ahh right.

P: 'I really hope I <you want to>, yeah but then you come in and something has happened. Somebody needs a prescription somewhere, you need to bring somebody to the doctor, you need to do this and do that and suddenly, all the lovely stuff of, of, of, supporting them in goals and activities and tasks gets put on hold. And at the moment in [the] house

we have this protocol in place because one service user was pulling the hair of another service user, we're not allowed as support workers, we're not allowed to leave them on their own with one support worker in the house. There always has to be two.

R: Right.

P: That's part of the protocol. So, <yeah>, for example, there's one guy over there at the moment and he's in his fifties, and eh you know he doesn't really want for much anymore, and that's not putting him down, <no no>, he likes his quiet life. And, ehm, all he ever wants is, this is the kind of thing that you're up against, all he wants is, maybe have a lie in in the morning, get up at lunch time or a little bit before lunch time, have a shower, come down have his lunch, have his breakfast in his room, come down, and then ehm maybe in the evening, because he's never he doesn't want to get up, you see, in the evening time then he likes to have his dinner and he loves to say 'will we go for, can we go for a cup of tea and a muffin?'

R: Ahh lovely.

P: On a one to one.

R: Yeah, yeah.

P: Can't do it.

R: Because you have to have the two people together with <yeah> the other person.

P: Yeah. Now, and then you'll get the answer back, 'well bring him out in the morning time or in the afternoon' <that doesn't suit, no>, no.

R: That's not his routine? Yeah.

P: That's not what he wants.

R: Yeah exactly.

P: And it's not his, it's not, do you know?

R: I do.

P: So, they are the sort of,

R: That's exactly. So this is really what I wanted to hear in that you want to support people, that's what's in your head, and then you turn up and there's things to be done. There's tasks.

P: There's tasks. Our tasks.

R: And the tasks have to be done?

P: What's priority?

R: Exactly.

P: I mean, we also have to, I'm a key worker, and there's the, I don't know do you know the support plan? Have <yeah, so I hear> you seen our support plans? Have you met our support plan?

R: No, I've heard.

P: Alright, well our support plans, for example the guy I'm working with, I became his key worker a year ago. And, eh, constant pressure, 'HIQA are coming, HIQA are coming, needs to be updated, needs to be tidied up, needs to be brought up to speed'. So, you know, and I'm doing my best with it, we have a crappy old computer that barely works. Now, I say that but other people can use it because they have better skills than I do. But for me for my needs, but you know, these are the sort of things and it really gets into your head, because I want them to have, I want them to have a really good support plan, I take real pride in my work, and I wanna be sure that the guy I'm working with has the best support plan, for his future and for anybody else who comes in. So I go and I say, ok well I'll update the support plan, and I go in to try and find the file, lost. So, I'm back now to rewriting it from the start.

R: Oh, you're not.

P: I am yeah. And I can't get to it. I can't get to it.

R: I know, it's head space.

P: I haven't got time. And then we had a meeting with our last [management], and [they] said, well what about 45 minutes a shift? 45 minutes a shift, is 10 minutes waiting for the computer to warm up, 10 minutes getting started, 10 minutes getting into it and then finishing, if you get that time. You need, there's no, and can we bring the work home? No, data protection. I'd love, I wouldn't have a problem doing it at home. I got the head eaten off me for doing that at the start. And so, you know, there's things like that. That's the, and it niggles at ya.

R: Well that's the question really what we're interested in, is how you do your support and to start with, it's what you want to do.

P: Very poorly <But you have tasks, yeah>. Not what, not if you read the policies and procedures and the expectations of government <that's it> and HIQA and management here <and your support plan>. Ain't possible. Ain't possible. And, I do my best, you know, I really do, like I work, I do stuff, and that's the other thing, you're not allowed to, you're not encouraged to do work in your own time. I mean I have no problem bringing the guy to a show or <ah that's, yeah>, we're going to his mammy next week.

R: Ah, yeah.

P: Not recommended.

R: Right.

P: Not recommended. Because we're in this professional era of, and eh I used to bring him to my house, to my sister, for dinner. Not recommended. Not recommended. So, you have that, and that's well you're and it was said, it was said to me by [management], 'he's not your friend, you're his care worker'. But, it's not, he is a human being isn't he?

R: Exactly.

P: Therein lies the debate. Therein lies the debate that'll go on forever. And, it's not recommended from the safeguarding thing, I did the safeguarding course here, and man, that hasn't even been examined thoroughly, in my opinion. Like you do a course, have you done your. And, this is the other thing, hundreds of policies and procedures, we have our in-charge person saying 'have you read all your policies and procedures?' Eh, no. 'Well I see on your one you have 50 left to do well you better get them done.' Like what do you mean, the question I've asked, this is where I get into trouble. 'What do you mean by read?' And somebody said to me, 'man you can't go in there, open it and close it and tick it off as read because they know how long you've been at it.' So, how long are you expected, some people are speed readers, lucky them. Most of us aren't. Is it not sufficient that we know that the thing is there? And, I've asked this before, I said, 'can the company, the organisation, summarise each policy and procedure and put it in a booklet and give it to the front-line staff?' There's a suggestion. Oh no, you've got to read them all. When?

R: When.

P: How? And take it all in? And then you have people going around, 'HIQA are coming, HIQA are coming and they might ask you', I've heard this story it hasn't happened to me yet and by golly I hope it doesn't, they ask you 'what is the eh, what is the policy for, something? And, what? You don't know, that's what you're going to be asked when HIQA come.

R: So, you are only given it in written form?

P: Yeah. Oh, not written, <there's no workshops?> No no no not, no workshops no.

R: You're expected to read the document is that it?

P: No, sorry, you go into Q-Pulse there, and you have your name and a hundred to do, to read. 'Have you read them yet?' 'Eh, no.' 'When are you going to read them?' 'You need to have them read.' <OK>. By law, it's ticked a box. But if you open it and close it, or open it and read the introduction and the end, two minutes, three minutes, not sufficient, maybe.

R: That's interesting.

P: Yeah it's scary. It scares the hell outa me. I joined the union because of it. When I did the safeguarding course, I said 'man, union time here'. And even doing the XXX training, I hope this all is confidential?

R: Oh no totally.

P: But even doing the XXX training XXX, really good, really really good. But, one, and I thought about it after, one thing that was said to us was, 'you're frontline staff. You know the service users better than anyone else'. Awh, great recognition! Eh, something happens; 'how did you let that happen, you know him inside out, how could you let that happen?' That's what goes through my head. Call me paranoid, but we're dealing with human beings here, we're dealing with, we're also dealing with, we're dealing with ehm, whatcha call it like HIQA or investigative, what are they called, what are they are, they're?

R: Quality assurance?

P: Quality assurance. And, they <and they're an enforcement>. They are an enforcement, thank you that's the word. Enforcement, you're dealing with enforcement here. So, you're 'oh they're the service user, or they're the care workers they know the guys much better than anybody else. 'I don't know how you let that happen? How could you not see that?' And little things, little things like even this morning, my guy, he goes home to his mammy every [week]. I was here yesterday, 'see ya XXX'. Had a great day with him got his hair cut and everything before he went, and eh, just this morning, his mammy rang because whoever, the [day service] over there they collect him and they were late and they hadn't contacted her or anything. Something happened, I dunno. But my team, leader, my leader, got the call and [they] come in, and very casually says, 'Ms X was on,' and eh, [they] said that eh 'X has a bit of a cough, a bit of a cold'. And I said, 'oh, did she yeah yeah'. And [they] sort of said, 'he was OK yesterday wasn't he?' Like [they weren't] here yesterday. I said 'yeah we had a great day yesterday'. Almost like, very nice and all, but it could be an inference, 'did you not see him having a cough or a cold yesterday? Why did you miss that?' That's how it could be, that's how I feel <that's how you felt about it>. Well no I didn't, but maybe and maybe I'm the one who <missed the cough or cold, OK, that's>. Yeah, and it's almost like, Ms X ringing in and she's a lovely lady and everything, but like oh yeah and <has a cold> and parents do get very <yeah> they get very worried about things you know. But, anyway so back to the question, what do I think of?

R: Back to the question, you come in with your head <full of> your aim would be 'I want to support the person'.

P: Yeah.

R: 'I want to support them to have a good day'.

P: I want to support them all, I want to support them all. Let them all have a great day.

Ehm, get the best out of the day for them, and especially it's funny, that house, it's residential, there are, eh, there's one two three guys who are in their, some are in their XXX, some are in their late XXX, right. And when I came here first, I often see the XXX jobs coming along, and I've been involved personally in a lot of ehm, sort of, facilitation work and drama and stuff over the years. And I often thought now like since I've been working here in residential, ehm. I made a decision just recently it's funny, cause I said, god yeah the outreach looks great you know like, golly gosh, early intervention and all that kind of thing. And ehm like I'm at an age now I'm XX right. Like, you know I was thinking yeah I'd love to get into that outreach stuff, really interesting work and advocacy and out there. And I, I just thought, these guys that I'm working with, they've, they're in their fifties, yano, they're in, they're older that we are, <yeah> let's be honest. And I mean what, I just want to give them as good a time, and understand what their wants and needs are. And like a real example is the guy I work with, and ehm like what do we do but like I was talking to him last year after a little while. Ehm, I'd known him because I was doing relief work as well with him. And we went for a coffee and I was having a chat with him and he doesn't answer directly really, and you just have to let it come and go. But basically, what I got from him was. Up to, about two years ago they stopped, XXX and another guy in the house for 20 years were going from here every morning, and over to XXX to the day centre <oh yes, yeah>. And that was their life, right.

R: Yeah.

P: And then that was all stopped with the new-fangled get into your community, no more going to congregated settings, day centres. Wonderful put it up in lights! Deh deh deh. So I said to XX, 'how's it going your new life and everything?' 'I miss my friends'. And this is autism who don't <meant to have friends>. 'We don't have empathy, we don't' and 'I miss my friends'. Now what he meant by, 'I miss my friends' is a very interesting thing, which experts beyond my capability would well be able to define and exemplify. But what I, because when you do bring the friends, they hardly even talk to each other. So, what does it mean, 'I miss my friends'? It could be 'I miss my routine, my old routine, I miss the contacts.' And he asks about people. But when he meets them, we do not know what is going on there.

R: No, we don't.

P: And change, for autism, and autistic person is just so difficult to comprehend, like but all this sounds great. So now XX is, he has a busy life, yeah on Mondays he does Men's

Shed which is out the back here, on a Tuesday he is doing he goes to pottery classes and projects, on Wednesday what does he do on a Wednesday, he doesn't really do much he has a lazy day. On Thursday he goes to [art]. And I'm hoping that'll grow, but it's a lovely space for them to be in, doing their community things and anyway, that's another day's work but anyway, he's going to that. And then, he goes home to his mammy, Friday he's back in and has the weekend. It's busy. And sometimes he says I'm getting a bit tired.

R: Hmm. Hmm. Yeah and they're the big questions.

P: It's so hard and I'm not I've got to qualify all of this, because I do understand resources. I do understand new systems have to be tried and tested. And we're on a road which is a positive path, hopefully in the long run. It's difficult at times, that's, it's difficult. Yeah you just want what do you do. You come in hoping to do the best you can, knowing that you may well hit on a few bumps in the road. But it's coping with the bumps in the road and maintaining a low arousal and keeping the lads calm and collected and as happy as possible within the resources that you have in that day. Be it time, be it your energy, be it their energy, be it being able to take them out in a car, and all of that you know.

R: Yeah.

P: I mean, we used to have a bus and now we have a little car that only seats one two three, three in the back and one in the front, four. We can't take them all together anymore. We used to be able to go on XX. Somebody said at a meeting there recently and I thought it was an interesting thought, again, this all sounds right. 'Ah well we're stopping all those driving them in buses together and you know it's not good for them it's good for them to go out on their own or individually or in pairs and all'. Is it?

R: Is it.

P: Is it.

R: Exactly.

P: Because by golly when they're in that bus and they're all together <there's craic>, and they did it for twenty years!

R: Yeah.

P: That's what they did. And they listened, one guys listening to the music and they, and it's not 'awe we're all together', it's not. It's autism. They're on their own together. It's a very extraordinary thing. There's a guy that I work with there and he, you look at him, you'll say 'hey how are you doing', *disapproving grunting*. Put him in a little group.

Unintelligible. <He just likes being there>. He likes being in the group.

R: And he likes watching.

P: Don't look at me. Don't talk to me. Don't come near me. But anyway, sorry.

R: I think that's, no it's not, I think that's the real thing of what having a friend is. Is, often it's being in the space where things are happening. And that allows people to be connected to the ability they have.

P: Maybe yeah.

R: And, we have to be careful as you say, about saying what's right and wrong when people are that different.

P: Yeah and it takes a lot of time. It takes a lot of time. It takes a lot of input, investment and time and energy. And all of that. Which <choice>, it's highly restricted.

R: Yeah and then this choice bit, because say if my job changed or your job changed, you'd kind of like to know about it and be prepared for it, or plan for it.

P: Yeah.

R: And when decisions are made because it's meant to be in somebody's best interest, that's a funny one. And when you start looking at your advocacy, who's best interests?

P: And, it's not a broad brush. Don't forget you have an individual here. Eh, one guy will react well to it, some guys don't like to be told anything going ahead. <Yeah they're different>. Other guys do. And there's no, but each of them are completely, they are just individuals and, and that's the difficulty, because we're trying to manage residential autism.

R: Yes.

P: And ehm so you know I mean it's all this stuff about the house, it's their home. Isn't it?

R: Is it.

P: Yeah and then people come and ehm even a neighbour over there like, might call over, which she has been doing for years. Now, we have a visitor's book.

R: What?

P: Anybody who goes into the house who doesn't live in the house has to sign the visitor's book.

R: For a policy?

P: Yeah. It's policy. HIQA. These are the things. These are the things. Eh, the PIC, if [they] call in, has to sign the visitor's book <sign the visitor's book>.

R: Right.

P: Who are we? What relationship are we developing?

R: Yeah.

P: For what? Transparency. Absolutely. Maybe the guys coming to fix the drains, visitor's book. But the PIC who's meant to be a friend, meant to be a support? The girl who lives across the road who's been calling for years. She now is being asked to sign the visitor's

book, and she does it regimentally because she's autistic and she's been told. She's like 'where's the visitors book I need to sign it', 'there you go, thank you'. Because I'd forget it. And if you forget.

R: Hmm.

P: If you forget. But no, no. There's all of that, and then there's the, yeah like there's so much. Administration of drugs during the day, you know, doing q-pulses, the q-pulse thing, and there's the incident reports and all that.

R: There's policies and procedures.

P: Policies and procedures and everything you know. I mean that thing, that thing I was telling you about the protocol that we have for the two guys. One guy pulls his hair, now he doesn't yank it, he just goes...

R: Yeah.

P: And, this this is the peer on peer thing, like by law, according to the safeguarding policy, if a guy, a service user, comes to another service users plate and takes chips from his plate, that's officially peer on peer abuse. And should be reported. No, that's autism?

R: Yeah or it's what you do with your friends, or?

P: It's what you do with, maybe you're making friends like that? Like these two guys, we say they're like teenagers.

R: Ahhh.

P: They're, they're sparing. XXXX. They're sparing, and XXXX, and he's a little old menace he has been and he controls people. I call him the gaffer. Because he manages the place. We're not allowed open windows. We're not allowed to keep bins in the kitchen. Awe it's you wouldn't believe like, even those little things that you think 'jesus them people who start to work they're like oh where's the bin? Oh, no bin.

R: No bin.

P: His lordship will not allow it. And like, you might, to open a plastic bag and put a paper wrapper in it, the whole thing goes out. So, it's just autism, but that's, but this is what, but these two that's sparing with each other and eh, sussing out the TV rights to the gissies, and rights to the sp-, and they're beginning to. I think they're. It's been a while, nearly a year. But they are beginning now to-. But they've been sparing. But that's gone out as three occasions as hair was pulled. And now, and now, and what worries me, awh, maybe I'm wrong. Maybe I overreact, maybe I shouldn't be in this job sometimes I think because, I have said at team meetings, I've said, this policy and protocol you've put in place here, if we're all gone tomorrow, those two XXX guys. Well, your man's XXX, and

the other guy is XXXX. Those two chaps are marked men in a system. One of them is a hair puller. The other's a chip robber.

R: Yeah.

P: Now. Another agency might take him on, they look at that and say, 'oh put him in with the heavy gang'. I don't know does that happen, you tell me if it happens or not.

R: Yeah well you're right about people being marked.

P: Yeah. For what?

R: Exactly.

P: For HIQA-

R: It's kind of normal.

P: For HIQA demanding that every incident is reported to them. Every physical abuse is reported to them. And that's a demand. And then it's recorded. So, those guys now are <have a record>. So, now you have Big Brother in action here. And we'll, I'll be retired, everybody who knows- and this guy, XXXX, he's been here all his life. He's one of those loveable guys you'd want to meet. He's full of autism but really sharp. And he, he, lets rip sometimes. But it's never, he is, he has had an awful tough history himself right. But he is, it's not that type of abuse, it's a gesture.

R: A little impulse.

P: And sometimes a girl, he might pull a girls' hair, long hair. But he'll let go, he doesn't keep going at ya he's not beating you up <attacking ya> or anything.

R: He just has an impulse.

P: Yeah and that's gone down now, and I just think god. And that's been going on for nearly 6 months now, and I'm saying, when are you going to end this?

R: Exactly.

P: The protocol's ridiculous, what we're doing. Because what's happening with the protocol is that the support, the limited support we can give to the rest of the guys in the house has been reduced. And, that's frustrating.

R: Yep.

P: You know. That man I'm telling you about, come on, you and me and bobby McGee, that's what I, we say. He has these little sayings... You me and Bobby McGee, will we go out for an old-, 'Who's going?' 'Just you'. And I say 'will we bring X?', and 'no, just you and me'. He just wants a one to one, a cup of tea and a muffin. And I say 'OK, it'll be you, Me and Bobby McGee, we'll go tonight'. But, I haven't been able to do it for ages. And, you feel so bad, you feel so bad for him.

R: Yeah, and I think it's, it's, is there any way for you to talk this through with anybody?

P: I've, well I've raised it at the team meeting.

R: that's it?

P: And, what you get is, yeah well what about on, in the morning, during the day when you can, when you can leave the guys? And I said no maybe he doesn't want to get up during? It's not the point.

R: It's not the point at all.

P: It's who you, yeah I don't think it's the point but maybe I'm wrong.

R: The bit about the, the bit about the, sort of protection. If that was a normal house, people do things.

P: yeah.

R: And people do more than rob chips.

P Yeah. You better believe it.

R: And people tend to take other peoples jumpers and people would certainly be pulling somebody's hair, and <absolutely>, normal life is <such is>, so this idea.

P: Such is. I've rented apartments with so called friends during my life, and my dinner's been taken. Hello! Do you call the police?

R: That's... [laughing]

P: I'm sorry. No because <No, this is actually>, you see this is the type of person that I'm afraid of being. What did you call me, a positive helpful person?

R: yeah.

P: I'm only speaking my mind but I feel I'm being terribly negative here all the way through this conversation <no no no, what, if we're talking>, and I don't feel it in the whole thing out there.

R: No, no. Yeah.

P: In the real world out there, so I'll tend to shut up now. I'm training myself. I've come to the point in my life where, personally, in that, I'm [age], I don't know how much longer I'm going to have to go on with this. I love this work.

R: You like working with the lads and,

P: I do.

R: that's your thing.

P: I love being the key worker with the guy I'm working with.

R: Yeah. Yeah yeah yeah.

P: And I love it, but you can't, you're afraid to offer any, I'm not afraid to offer, but I feel I'm always being deemed as being negative. But I don't have the answers, like either, and I'm not being negative, but if you don't air these things.

R: Hmm. And it's not, you're right. If you're frontline staff it's your job <we know them better than anyone else>, to bring forward, well to bring forward something for discussion. But the way that the standards or whatever we call them are being impacted. Now, if you really got into person centred planning and person-centred care, there's usually big discussions around ehm, the fairness in terms of resources and responses and use of resources that one person impacts on another and all the rest. And they have to be kinda worked out.

P: Yeah.

R: Not just a, a rubber stamp saying OK now you need two people and you can't leave those two.

P: Yes.

R: That's that's, not that,

P: But we don't, and XXXX... he's a lovely kid, very bright, nonverbal. Very energetic, a lot of rocking and a lot of vocals 'whayayayay', all that. And that's in three guys, four guys who've lived there all their lives and they're in their forties and fifties and they are ready to just chill out. And this guy's going around the sitting room 'yayayay' <ah> and picking up the television thing, and switching the stations, doodleoodleoo.

R: ahh, he, yeah, ok.

P: And yes, we're saying, oh yes you know, we're trying to figure out, well what are we guna do here. Yes, we'll get a TV in his room. Get a DVD in his room. Get a radio in his room. <No>. and all of this, and well not just that but also then like sit down and discuss it with him. You can't, you've got to allow the other guys and doodleoodleoo and all that. Yeah, but it's still there.

R: Yeah.

P: And, you know.

R: He's impulsive.

P: He's impulsive.

R: That's his condition.

P: God bless him. God bless him.

R: Yeah.

P: And XXXX. And ehm, you know, I'm a bit upset at the moment because ehm, he goes home on a XXX, right. And I was on the shift XXX morning, and on a [that] morning what we have to do is, which he doesn't, his routine, is he doesn't want to get out of bed. Get him up, get him dressed, get him fed, get him into the car and drive him to XXX. To be in XXX before half past 9.

R: Ooooo. The traffic.

P: No no. That's it. Because [day service] have their daily plan, and he needs to be there to be included in the plan. So, last XXX, working with this woman and she's really good. Now she's not full time, but she's, she could be full time in a minute. She has great instincts. Do you know the way if you're working with people and they have the instincts. So, I said to her, I said, listen, tomorrow morning its D day for X, it's [day service] day. I said, would you mind, because XXX and he is surrounded by aunties and mother, it's all women. So, my theory is, 'mammy', I said to [staff], will you mammy him tomorrow morning? Get him up, get him dressed, you concentrate on that, and I'll do the toilets and do the meds and be ready to go, whatever. So, we did. She got him up, she gave him a wet shave, to get him nice for his mammy and everything as well. Ehm, so anyway, long story short, went off doodleoo. I come into shift yesterday morning, 'XXX, there was a problem, ehm, the mother and the aunt rang about X'. And I said, what what happened? 'They're really annoyed about the state he was in when he got to them. And I said what do you mean the state he was in? 'He was wearing other people's clothes.'

R: Hmm?

P: No, don't 'hmm'. The mother was furious. XXX she's highly emotional. Which is fine.

R: Yeah.

P: But this is how it was put to me. And I said, for god sakes, I mean. What what what, I mean, OK, right, well, I said, well let me tell ya. We decided, myself and the [staff] I was working with, to mammy him. She wet shaved him, went to all the troubles. Now, if there's wrong clothes in his drawers, at seven o'clock in the morning, in the dark, we're not guna catch it.

R: Of course. Yeah.

P: And, ehm, he said, 'oh yeah no no, now don't get me wrong'. But I said, 'hold on a minute, what's going on here?'. 'Well, no well I've been speaking to them'. I said fine. 'And our new [management's] guna talk to them, and he's told them', this is what I was told, 'he's told them that he's raising a complaint about it'. And I said a fucking complaint about fucking what. I'm sorry, I just,

R: No no yeah.

P: I just lost it. I've apologised to him since. You know because it really annoys me.

R: But, yeah.

P: It really annoys me, I said, 'look I know X's situation, I've been bringing him to his mammy and XXXX. What a lovely lady. And like you know, and I said 'do they think we neglected him? By the way they've talked to you, you've got to tell them '. I don't want

him, the new PIC saying, 'yes certainly I hear ya I'll put a complaint through.' He should be saying, now 'X and X would never neglect X'. But, no it's back to, a complaint's been put through, the new procedure is that already they're going to get labels online, they've ordered online labels. Eh, to be ironed to his clothes with his name to it. And, I said 'well, while you're at it, you may as well get labels for all the other service users as well'. And I said to him, because at the moment we have a situation in all of the houses, which has been the situation for almost a year now, that we've had changes in, in, the team leader. Not the team leader, the PIC, the in charge person, the ICP or the PIC. And we have change in that, we have staff been out, and the house has been infiltrated by loads of eh, they can't get staff, and they can't get, ehm, what was I?

R: Agency? Relief?

P: Relief, relief. And there's relief work coming in through this house for the past year. So, nobody knows who owns what pants, you put labels on them but like. So, I said, you know I said, 'but that's not, seven o'clock in the morning. Making sure he's clean, washed, <not upset>, shaved, look, going out the door, throw a coat on, into the car off we go, looking great. 'Oh, he's got the wrong t-shirt on, wrong jeans'. No, they weren't actually but they, look. The comment I was told she said he looked like a tinker. And, OK, XXX, but then to hear that [management] was going to raise a complaint through. I said 'a complaint? What language are you using here? It wasn't a, there's no complaint'.

R: Yeah.

P: And, I've asked already can I phone because I know them, can I phone them and go and say, 'excuse me I was on that shift'.

R: Exactly, and the clothes aren't labelled.

P: The last thing, I would never imagine to neglect X. We've been giving him so much, and for you and even to the aunt. Like, all you do is concentrate on him. And she did a great job, she's so good got him out of bed. Try getting him out of bed, you know, teenager like. Get him out of bed, awh man. Gets out, gets back into bed, all that stuff. Put your clothes on, back into bed, out of the pyjamas, leave him, right get dressed now, back into pyjamas, back into bed. Seven o'clock to nine o'clock didn't leave here till ten past nine.

R: God.

P: Wash, wet shave, wash, duh duh duh. Anyway, there you go. That's an example.

R: That's a very good example because it shows the kind of conflict in the person-centred piece, <yes>, and then, what I really wanted to know a bit more from you is, you've said now, you're on the ground. But, the support that you're looking for, to deliver person centred, that's the next piece. So you say you talk to,

P: The facilitation.

R: Well you talk to, you talk at a meeting about this, and then basically the issue comes back <monthly team meeting>, monthly.

P: Yeah. It's all the time really. Let's be honest, it's all the time the guy our in charge person. I wouldn't take their job on if you paid me a million pounds.

R: So, it's looking for ways, one of the questions is is there anything that would help?

P: Their job, their job is wrong. They work shifts like us. They should be doing nine to five, administrating.

R: Yeah.

P: If you're an administrator, administrate.

R: Yeah. Therefore, if you think we need labels, we put on labels but you get on with that.

P: You could have spotted that.

R: Yeah. You could have.

P: Like, that's been,

R: That's an administrative, a system thing.

P: And it's funny, it's one of the things that's been annoying me for ages and I was going, ah, and I said, nah I'm not going to raise that at a team meeting.

R: Yeah.

P: I'll be like an old fuddy duddy. But I notice socks in the wrong, not in the, in the wrong place, knickers in the wrong. You know. And the, one person will say 'awh that's X's, it's even got his name on it, Jesus, it's dark, what's going on here'. You know, anyway.

R: So, it's, it's the next piece. Well, the last question is, really, we're asking about how you support people. So,

P: I hope we're not going on are we gone on too long?

R: Well, what time are we? Well, really, you kind of answered everything.

P: Have I?

R: Well really the big question is what's in your mind and how do you support people? So, you go in trying to support people. And, then it's, what I'm hearing, you're getting on with your day. But it's the tasks that have to be done and then things change. But now, we have a set of policies and procedures, that you aren't on top of, you can't have a chance to read, you are expected to read them as a way to understand them, there doesn't appear to be any other way to help you process them. And, then, when there's something wrong, it's looked at from a procedural point of view that's now looked at like a complaint.

P: Yeah.

R: So, it seems to go up and back down on to you. Whereas if there's another management structure, surely that's their job.

P: It keeps coming back on us. I'll give you another example.

R: Yeah yeah yeah.

P: I'll give you one more example. There's one of my colleagues in there right, [they're] wonderful, like [they're] from the old stock and trying to change, and between you me and the wall, but [they're] brilliant. And [they're] a hard worker. [They] vol, [they] XXX, alright. And [they] volunteered, [they] volunteered to ehm.

XXXX.

R: So, where we're back to now, is really the feedback <oh yes the example> of how you're on the, the sort of the cutting edge. And then how it's actually interpreted by your procedures and policies and management.

P: Oh yeah. I'll give you this example. This is a prime example. Anyway, this [staff], [they] volunteered to be the health and safety officer in the house. Wonderful. Little things started to happen. All of a sudden, we're told, first, here's one instance, for instance. We have red, we have blue green and yellow rags. Blue for kitchen. Green for general. Yellow for cleaning the toilets. Get them in little buckets, little plastic containers, and locked it. Edict from health and safety you are not allowed to lock any door, any more. Restrictive practice. We've a guy, who likes to open the door, take the yellow, shitty, keeps putting it back in the washing machine on top of clean clothes, into the dryer.

R: Awww.

P: So, I was saying to this [staff], 'can you go back and tell them that this is fucking ridiculous', I said. 'This, we should be able to lock them away'. 'No, restrictive practice, we were told restrictive practice'. 'Well tell them it's a stupid one'. 'No no no, they've told me it's a restrictive...'.

R: Yeah.

P: And then [they] start taking it personal from me cause I'm starting 'for fuck sake will you go and', and then, and this. So, anyway that went on and then one day. Oh, I kept locking it, and she said 'well if you're locking it when you're on shift, you're not meant to be'.

R: Yeah.

P: So, I kept locking it on my shift. Because fuck that.

R: It's a danger.

P: I came in on one shift. I came in then one shift and eh, all the locks were taken out.

<Huh> Yeah, so I couldn't lock it any more. Right. Health and safety. And I said 'for fuck

sake, did you not go back and tell them'. 'No no no, that's the edict and I've taken all the locks out and that's the way it is. I being told by the Gods that...' So, anyway, the next one, ehm, the next incident I had. Oh, sorry I've forgotten it. But it's, what did we have, we had a terrible, we had a terrible falling out over it. It's really important because it really gives you an example of it. Ehm, I've lost my train of thought I'm sorry. Ehm. Oh yeah. All of a sudden, we're being told, you're no longer allowed, oh yeah, you have to buy particular cleaning gear. You can't buy Flash, you have to buy Tesco. You can't buy Tesco, you have to buy, such and such.

R: Yeah.

P: You can't buy this, you have to buy that. And, as well as buying that, you have to get the data information. Right, now this is coming down from this health and safety leader committee, right. So, I'm on the shift one night with this, with the poor [staff] who, and I mean it. [They] volunteered right. And, [they're] going around and [they're] saying, 'no, no, no, X bought those Tesco Flash cleaners, whatever, multi-surface cleaners, yesterday and I've got to get the data sheets for them. I have to get the data sheets for them, we don't have the data sheets. And I said, 'what?'. 'Oh yeah no she bought them and we're not,'. I said, 'what do you mean the data sheets?'. 'I've got to get them I've got to get them'. So, I said, 'ok can we go, let's go and google it and have a look at the data sheets'. Couldn't get anything. Couldn't get anything. Eh, so I was saying to [them], 'listen this is fucking ridiculous. And I said, they've employed some guy, an expert, which they have. To advise us, on all of this. I said, 'you go back and tell them to get that guy, or the health and safety committee, to give us a list of products we can buy <Yes> and the data sheets with them'.

R: Yes. Provide it.

P: 'And then, all you have to do is implement it'.

R: Yes.

P: 'You don't have to every time we buy a bottle of washing liquid, get it approved and get a data sheet!'. And, I was talking like the way I was talking to you earlier on. [They] took it really personal. And and there was sort of friction, you know. And because I was only, I wasn't arguing with [the staff], I was only arguing with the idea.

R: With the idea, and how it was being implemented.

P: So, in the team meeting I raised it again. And, eh, my guy, my lead, team leader spoke to me afterwards and said like, you really upset [them]. And I said, well, man.

R: The problem to solve here, isn't at your level. It's the next level, as you say that information should be made available, and all you do is implement it.

P: And that's what that was all I was trying to say and [the staff] was taking it really personal. And its not. But, this is the problem. They're doing things to people that's not fair, it's not fair on [the staff]. And, [they're] not, [they're] not,

R: It's a different level.

P: It's a different level.

R: Like you were saying, your nine to five people should basically be doing that kind of

P: We're trying to look after the guys! And, every time they come down and say here's more. I remember three years ago, before, three years ago, when I was here. I was working in another house, and XXX. I remember it, when when HIQA were coming, "HIQA are coming!". All of a sudden, for each service user, we were told we were given a tonne of paper. 'here's the support plan, fill it out'. I started filling it out, huge amount of work involved. Fill it out by hand. All of a sudden, 'oh no no no, it's coming down online, fill it out online'. 'Oh no no no we've changed that, we've done this'. Ehm, so, that went on for a while. And then. That went on for a while, and then, days, just days before HIQA were coming for their first announced visit, that whole area over there was full of people typing up support plans for all service users in this campus and beyond. And eh, got it done. Well done. Brilliant. Got it done. Here, here's a support plan. Might ring and say, whats this about someone, do you know blah-de-blah. Anyway. Done! Got through the HIQA thing, right. Fabulous. It's nearly three years now, HIQA were coming again. No training, nobody's come to visit us. Tell me, the key worker, how to do the support plan. No.

R: Oh, my goodness.

P: And, then you're just told, 'that support plans out of date, you've got to get it, too much in that support plan, what's that doing there, why have you put that in, that's all wrong'. So, I took the support plan of my guy, which has very little in it, well it's all out of date and ancient, but it's the only stuff that's there. And I'm not happy about it because I have to start from scratch again, and I ain't getting the time to do it. And, so I was told by, my, 'well you have too much in there, archive it!'. And he gave us archive boxes. So now my support plan is pretty bare, and everything's in an archive box, and if they come today. Well it was all, end of the year, archived. Not happy about it. I am not happy about it.

R: No.

P: And, the support plan is one of the, it's the most essential thing!

R: Yeah.

P: From my point of view as a care worker, maybe there's more important stuff that the organisation has to look after. But, it's again, administration. Give me somebody

therefore to type it for me. Give me some, no no. Here's a shitty old computer that the cursor goes mad on it's own and 'oh well, everybody else seems to be able to do it'. Well I'm having difficulty and the poor [staff] I was referring to there about, [they] can't even switch a fucking computer on.

R: Yeah yeah yeah.

P: Excuse my French, do you know what I mean?

R: Yeah.

P: And eh that's the thing. And that's really annoys me, because I want, because I'm not thinking about HIQA. I want my support plan and the support plan right for my client, or my service user.

R: And this is back to where we started, with what's in your head when you come in.

P: Yeah. That wrecks my head.

R: And what's in your head is, you want to do support, but you've got all this procedural.

P: '45 minutes, I know you can do it. 45 minutes a shift I know you can do it. You guys did it before you'll do it again'. All that patronising stuff from management. 'You guys, you can do it. HIQA are coming, huhhh'. Give it to HIQA and get the bad marks and then move on. I've heard a terrible story just recently, about other organisations that actually, I dunno whether, I hope it's not true but they actually create situations, or incidences that make the guys look a lot worse than they are. And therefore, they go to the HSE and they say 'this guy is a real problem we need more money to care for him'. And they're getting more money for it! That can't be true. If that's true, at least [this service] are honest agencies. We're really honest. Like, and actually, all the frustrations I'm saying to you is because, it's because we're bloody honest. And we're running, we're not, and I hope, we're not, I hope that protocol thing I'm talking about isn't the beginning of, a thin end of a wedge.

R: Yes.

P: But, if that's what is being done out there. Yeah, do you know what it is, we had the church forty years ago <that's right>, this will happen in twenty years' time it'll be on the news <yes, it will, yeah>, another scandal. All these private companies coming in and they're milking it.

R: Yes. Yes.

P: And they're putting guys apparently into cars, like, what did you do with Joe today? Yeah I took him to XXX... You know. Why? Are there no piano lessons in your locality, in your community?

R: Yeah.

P: No. drive. Just keep them driving. That's horrific.

R: Yeah.

P: If that's true, don't.

R: Yeah. No, I've heard, other anecdotal things that would scare ya.

P: So, after all our talk

R: Back to [this service].

P: I love [this service].

R: And they are,

P: Because at least it's being honest. And they are honest. And they're struggling, struggling. And I think our management might need help, but that's, see I was a XXX, I worked with XXX for XXX years, and you know. They need, maybe they need help. And that's, I'm not criticising, but I hope that they, maybe doing this is the start of it. Maybe they need some sort of help, themselves, to manage us.

R: Yeah, and it's managing for a person-centred service, that's genuine to their core and their values.

P: And, it is.

R: That is [this service's] values.

P: Awh.

R: Yeah it is [this service's] values.

P: There's no doubt about it.

R: No. That's, I agree.

P: And the sad thing is people who have worked here longer than me and all, are beginning to feel, disenfranchised, ehm, not no, they just feel very, as if every move they make is being questioned. And they can't do right from wrong.

R: Yeah.

P: And that's a bad way to have your staff.

R: Because your staff are the most important people for your service users.

P: Well. That's about it. And like, don't say we know them better than anybody else, that's a lovely thing to say. That would scare the shit out of me. You know. If management think we know them better than anybody else, hello? I'm only a care worker! Bottom feeders. Where are all the experts who are meant to be, eh you know? The psychiatrist review, we do a review of so and so and so and so. Will you do the review, yeah go along to the review. Medical review. Every three months. Whatever. I don't think he'd know my client if he met him.

R: Yeah well, he couldn't.

P: He never meets them

R: Yeah.

P: How can you do that? These are psychotic drugs!

R: Yeah.

P: Based on my word and the nurses word?

R: Yeah.

P: This is all wrong. This is the next scandal. And it's not [this service's] fault. And they're there, the government and HIQA. And HIQA's like. And I love the whole idea of HIQA, like I'm not, bring them in. But please god go to the government and tell them 'shame on you'. Anyway, that's another days work. Back to where we are now.

R: It's another day's work but back to the advice, the real last question is there anything that could be done that would help? And you've been raising how, management doesn't really support the, the kind of quality care.

P: Not deliberately. And not deliberately.

R: And they have a headset that's process driven that isn't around personal supports and quality of life. That's what I'm hearing from you.

P: I would think that god bless them, they've been hit with the HIQA, the HIQA virus.

R: Yeah.

P: And, I don't blame them.

R: No, no.

P: It must be horrific. It must be horrific. But, I come from the private sector, I worked with XXX for XXX years. We had our main accounts, right. And they have their quality teams. And we had, what you call an open-door policy.

R: Really.

P: With really big accounts. And you would know how much, how much profit we were making from the business we were doing with them. And how much eh, how much we pay for raw materials, where we buy the raw materials, how the raw materials were made. Open door policy with these really really really powerful strong main customers. Top four, top four customers. The quality team would come in once a month, inspect us, and give back our... But it's the old story, how you look at this, it's a work together thing. And that business, that's high cut throat business. You develop a relationship of trust, and this is just making empty boxes, right? Printing and making empty boxes. The element of trust, of course there's commercial under your arm stuff as well, but oh, open door policy. But they would come in they'd see how we do things, they could ask me what I do and I don't even, I wouldn't be even on the account. But, there was that forensic. And it's very

like what HIQA do. But, the relationship is, was not a relationship of fear. That we find, they give us, targets, yeah?

R: Yeah.

P: And they'd say, 'I want that done in three months'. And we'd do our best. If we don't get there, they're not going to pull the business. They're going to say, 'ok why didn't you get there? Let's work together'. Because some of their experts were better than our experts and they could always tell us how to run our company. XXX. And that relationship is a trust relationship. And what I don't get the sense of, and the only people we have that have been sent to us from management, is that HIQA are in that relationship with us. I haven't got that sense. It's 'watch out, HIQA are coming any day now. And if it's not right, if your support plans aren't up to date, if the house isn't, if the lads aren't right, we could be in deep shit. You didn't hit 80'. Our house fell below 80, on some internal audit. Major pandemonium about it. That's where the 45 minutes a shift came from, to do your support plan and your paper work.

R: Yeah.

P: And 'I know you can get them up to date, get the ready and HIQA ready'. HIQA ready? What are ya aiming for management? What are we aiming for? What are we doing? What are, what is HIQA about? Let's meet HIQA. What are they, are they, are they talking to you. I don't believe this.

R: Probably not.

P: Because I remember, I remember now this is the other side of it. In my business, I was a XXX, and I'd be going around. And I'd have internal sales people working on my account. And, we'd be every day, fighting hammer and tong to get the product right, to look after the complaints, to fix quality issues, bang bang bang bang bang.

R: Yes.

P: And then, then you just know it, our chief executive and the purchasing director are out in the XXX playing golf, having dinner, all is well.

R: Yeah.

P: And they're talking about the big picture. And the future. And we're all down there, stressing out. And that's how it is, that's. but we. It wasn't as bad as here. Because this is like 'if we don't get HIQA we get closed down, or you'll be in deep shit'. And there, there could be consequences. The fear of consequences? Like eh disciplinary action maybe?

R: So, that fear culture, doesn't really fit in a person-centred place <no>. Where we're all meant to help each other.

P: No, and there really is a fear culture. I mean, I'm not that bothered, but I think some people who have been here a long time and haven't had the, it's a bit unfair, but life experience, for the sake of it.

R: Yes and the confidence.

P: Like I mean I can compare, I can see HIQA is a quality control system, but should be there to help us progress and improve the PCP.

R: It is. It is.

P: Well, it doesn't feel like it in the, you ask anybody working here.

R: But how is that been interpreted? Do you see? Into the fear.

P: Yeah.

R: So, from a management point of view, there's a real, what you're actually saying to me is that what would help, is a management perspective needs to be looked at <needs to be managed properly>, as you say, collaboration and trust, around quality. Which is an ongoing thing, it isn't just 'I've got it in a book'.

P: Yeah. Oh you can't talk, you can't say that, like. You know, you can't say that about the, about the ehm. Oh and like at the team meeting when I was saying, 'listen', I was saying to XXX my guy, he's a lovely fella as well. 'What are they doing, asking XXX, to do this?'. I said, '[they are] being distracted, when I was with [them], [they were] being distracted. [They were] running over to the [other house], to see if somebody had the data sheets there, or how to get data sheets, or [they were] told there was a phone number. And then [they were] running over to the [other house]', and I said 'they were being distracted'. And then, I got, they, they, they 'excuse me', they said, 'are you saying I was distracted from my job, and that I can't do my job?'. I said, absolutely not. But.

R: That task, shouldn't have been put on [them].

P: But, but my team leader says to me, '[They] volunteered for it, [they're] happy doing it. Why are you raising it?'. And I said, 'cause it's not right'. So, that's where at the start I said to you I'm trying to keep buttoned up here, and eh, this is the best supervision I've had in years! It is! I mean, that's the other thing, we have supervision here, and when we do, what's the point in having supervision with your team leader?

R: Yep. Yep.

P: I don't get that.

R: Yeah.

P: I never understood that. They do say that there's a psychologist that you can go to, but that's. but that's no use. Like this, this is brilliant! But, come right back, come back to the positive.

R: Well back to the question about how we help?

P: Come back to the positive thing, you're here! You're doing this on behalf of [this service], isn't it?

R: Well, on behalf of [the researcher], who is in [this service] and they are supportive of this, and they want to know what's happening. And they think it's important to ask staff.

P: Ah, well this is great?

R: But they actually do, there's a new, new management person?

P: So I believe I don't know his name.

R: So, apparently this has value.

P: I don't know his name!

R: This has value because [this service], I'd have known...

P: Neither do, neither do the parents. Neither does my guy, the parents, it hasn't even been announced.

R: Oh, has it not?

P: Well, I haven't seen any announcement. But he is, but not even a letter to the parents, <to say, hey>, and our PIC over there?

R: Ok, so what we'll be able to take away from out of this <that's a different kettle of fish>. Yeah but actually, what we'll be able to take out of this is how to make it better. Would it be, we're looking at the culture; we're looking at the culture of management; the culture of support; and we're looking at the ethos that was there, and now with these new structures it's come into this fear, authoritarian. That's not a collaborative, co-operative.

P: My fear, there are people here and I remember when I came here first I did my training course. The woman who interviewed me, it was pre the new interview system, which pfff, anyway. Ehm, the woman who interviewed me and then doing the training and working as a relief worker for a number of months, number of years. And I did the number of months when I started and then I did the training the autism training and everything like that. And I did say, genuinely, I felt it here, that there was a true compassion, by the people who were working with the service users. A true true compassion. And also, the management.

R: There used to be anyway.

P: And I felt, yeah. Well, I think there still is. And, but it could be snuffed out because of something that could be turned into something really really positive. Yes, a quality control system that's managed, and managed, if there's something that needs to be done, we can't do it without the support. I'm, I'll do anything, but don't throw it at me.

Mushroom management, I've said and I've been told stop saying that, you know. Well it is mushroom management. But maybe it's not deliberate, maybe they don't realise. But this is fantastic and I love [this service] and I wanted to go on and on and grow. And there's some, the outreach area, the people who are working in that, the way that's been run, that sounds

R: Yeah. That's been thought through.

P: I've known people who have worked, young kids, I call them kids, but they're young twenties people, who have worked here, as relief workers and full time and they've moved to outreach. And they just say to me, 'man, it's another planet'. So, poor old residential, it could be what I was saying to you at the end as well, it might be a cynical theory, but a theory all the same. But I've decided to stick with the old fella's, cause I'm a bit of an old fella meself, and also, I just want to give them a bit of a, now I'm not saying they've had a miserable life, but their lives haven't been terrific. And they've been lucky guys that they've got into [this service], it could be other places. And some came from other places. But, all I'm saying is that ehm, maybe they should look at the model of how outreach is being managed and that would be a starting point. Because that sounds completely different to what's happening here in the residential area. Maybe I'm right, maybe I'm wrong. It could be a starting point.

R: Well that's a really good place to kind of leave it, in that you've actually come up with solutions, and that was what the question was about, was there anything that would help.

P: Yeah and I, well what I would think is that they need to, well what I'm saying here is that, and if I sound, if I get, I'm often conscious of if I get a bit urrrgh. Angry, I'm not angry, it's not an anger, it's a concern. Eh, and I think management should have a look and not 'awe have a good look at yourselves you're useless'. No, just re-appraise, what message are you giving to us about HIQA?

R: Yeah.

P: About how we're doing our jobs. About what support is available and what could be available and what we could do, and it's <and and>, and maybe, if there's a resource problem, then like is there a resource problem? And if there is then why is there resource problem and what can you do to improve that. Maybe there's not, you guys know ways around that. But I hope they don't play the game, the rumours I, anecdotal rumours, I hope we don't go down that road. That is horrific. And that's what would worry me about what's happening with my lads in that house. But, we have to do it. We're told we have to do it. Then, management have to report it to HIQA. And then, bing, these guys are marked men. Anyhow.

R: I think.

P: But yeah, how.

R: We'll leave it at that, we've got enough.

P: Is that enough, is it wow?

R: Well there's tonnes to go back. Because it's really all around how you support people.

P: Yeah.

R: Ultimately, what's in your head and then what actually happens? But we've got it.

P: Yeah. But I hope I'm not being negative.

R: No, cause the question is, is there anything that would help? So, we've tonnes of things that would help to get back to the core thing, which is, the lads.

P: Yeah, yeah and I do believe one of the big things that would help is that administration end of things. Stop the, stop, change the, the job of the in-charge person. That's bullshit, I mean they're working on shift. When they're working on shift they're doing paperwork so there's one person doing all the management, like that, that's broad.

R: Yeah.

P: But, most, and that, that's what they should be doing. Administering. Looking at our support plans. Saying here now let's get this bit done. Yeah, we'll do this, yeah lets.

R: Yeah that's leadership.

P: Yeah it is leadership. But it could be done. The guy over there at the moment, he's brilliant, he'll be gone in a couple of months cause XXXX. And he's filling in cause our guy is over there filling in <yeah>, and all of that, but nine to five. And if they are executives nine to five and overtime I dunno, whatever way you want to work it. Make them into executives, but not go down the business end of things but into administration and help us administer. Because that's the only support we need. The rest we're great at, and we are! And that's what HIQA say, they go in to the houses and they see the guys and they see the, that is. But let's make it even better, let me have time, to here look this is the sort of thing, I was just going through. I'll finish on this, I was just going through this with X. Here's look, the weekly key workers meeting, this is where weekly we're meant to sit down with your – take weekly out of it! Key worker, meeting, weekly. 'Did you not do it this week?', 'Did you not do it last week?', 'why didn't you do it?'. Do you know what I mean? Because we don't, and he doesn't want to. And we'd like, weekly? What? What are you talking about? But, that's where I, this is where I started last year, and you know, strengths and interests, like, quick. It should be typed up though, should it. Do you know what I mean?

R: No, exactly. Yeah.

P: But this is the kind of thing, and I, what I found out was, I was going through it and it jeepers, you know, X named all the name's you know.

R: Hmmm, that's lovely.

P: Yeah. And then like, and then we, but looking back, you can see, all this is necessary, I don't disagree with it, because looking back you can see yeah look at what he has done. We got to Manchester this year. His first time in an aeroplane and all that kind of thing, you know, but. And then I've got his, I had a little talk with him last week, and I have his goals and all down here. I haven't done these, these, last years haven't been entered into his PCP, never mind next years. But I'm doing it.

R: Yeah.

P: So, if it's a few scraps like this and here you are Mr. HIQA, it's happening <it is happening, and that's> but it's not in the PCP format where the photographs move up and down all over the place.

R: Yeah yeah yeah well someone could help with that.

P: Oh, put loads of photographs in? Yeah yeah.

R: Yeah yeah.

P: Oh then you're talking, don't take photographs. One minute we're told, eh you're out and about take loads of photographs and WhatsApp them to me. And then your told <confidentiality>, safeguarding, data protection, you're not meant to have any photographs. I have thousands of them, I don't know how to delete them! Or I'm afraid. But you know.

R: Yeah.

P: But so. The work is being done is what I'm saying, to the best of ability. It seems like the administration monster is interfering. Whereas it should be supporting it, it's not. And and, long live [this service] that's all I'll say. By golly it's a great place, and their ethos is lovely. I really mean it, I love working here. So, there you go. Is that enough?

R: We'll leave it at that. We've tonnes, we've tonnes, we've tonnes. Thank you very much, I'll just make sure I stop this now.

Transcript Five

R: So, I suppose straight off it's about how many years have you been working with adults?

P: Eh, yeah so, I started 3 and a half years ago. I've worked here the whole time. Yea so this was my first job in social care. I worked for XXX for years.

R: Oh, did you? That was very different.

P: Oh, yeah a lot well I was sort of looking for something different to do, and ehm one of my colleagues... I was telling him I was a bit sick of my job and he said oh would you ever think about doing social care, you know. And I was like going oh I don't know what's social care, is that social work? And he was like no it's a bit different. And then yea I rang up a month or two later as he said they were looking for people and you wouldn't necessarily need to have experience, and eh it's more about really your personality you know. So, eh... I sent in the CV, did an interview have the job and I'm here ever since yeah.

R: So that's a real, interesting change. Like, different world.

P: Yes. Definitely, oh yeah. There was a lot... although you do see, you know, similarities I suppose in the sense that eh, when I first came to [this service] there was a lot of a social model of care, you know. Whereas definitely in the last year or so there's more of, stuff that I recognise from my old job, say...

R: Yeah, your quality assurance, standards, procedures...

P: KPI's. Like, key performance indicators and all that kind of thing.

R: Oh yes yes.

P: Oh this looks very familiar, you know.

R: All around quality. Yea. That's interesting because you've seen it, and then when we get further down the questions, we'll be asking things about how from your experience in working in the services, is there any changes that would help. Like, and often when you've got that lens of looking outside in from the performance indicators and all of that, you've got that head and how to look at things.

P: Well.

R: Well, you have some experience.

P: Sometimes I found, I was reading through the questions and I'm kind of going, oh I'll have to have a bit of a think about this. You know.

R: Yea and that's why you get them.

P: And sometimes it'll kind of come to me later on, you know.

R: Yes.

P: Just even on the drive up today I was going, oh yea yea I might think of that. Or I had something... in my head. But sure, we'll see where the interview goes. Stuff may only come out, or come to me while we're speaking you know.

R: Exactly. So, in how you work, on an average shift, about how many people would you work with at any one time?

P: Yea so I work, like a 24hr shift, so start at 10am, do a sleep over then that night, and finish up at 10am the next morning. But as well as that I would do a couple of ten to sixes throughout a certain week period as well. The staff number has increased the past few months because we've got new service users added on that need you know, overnight staff. So, we're actually in a bit of a transition as well, where management has changed, bringing good ideas, because I think we were getting a bit stagnant for a while. So, I think going into 2018 there's going to be some good changes coming. So, yea, 2 to 3 people.

R: Right. So it's quite intense?

P: Well. Two to three on a 24hr shift. Say, I might meet someone at 10am and be with them until 1pm maybe.

R: Oh, right, right. Yea.

P: Then have a lunch and I might be meeting somebody else at 2 or 3pm. Say 2pm. And then I'll be back maybe like 6pm or 7pm maybe with another service user to do a sleep over. So that would be kind of it. Now, some days, I might just meet the one service user a day. I might be doing some admin work or...

R: Yea. So, normally you meet people on their own? Is it, one on one?

P: One to one yeah.

R: Ah yeah. Well that helps us. So, then how do you support the person in their hobbies and interests? Would that be part of your...?

P: Well, eh it's interesting I was thinking of that one as well in a question. So, some of the guys that we support, well a lot of them, so there's [X number of] guys that need overnight support and we would be with them throughout the day, quite a bit. There's other guys that are living out in the community on their own and they're kind of living their own lives. And we would link in with them on an outreach basis. So, as regards hobbies, they're kind of self-sufficient. They're kind of doing their own thing, yea.

R: Really. Yea, that's it. They get on with it.

P: they would generally do their own thing, yeah ehm. Like one of the guys would be into a lot of IT stuff, which I wouldn't really have much, like, they'd be nearly guiding you.

R: Yes.

P: Do you know what I mean like? I wouldn't really be up to speed on that sort of stuff you know. Like some of the guys then they're in gyms, yeah, they go independently.

R: Yeah sorted.

P: One of the guys goes independently, he goes five days a week, yeah.

R: OK. So really, what do you do? Is your focus supporting him in the routine, or is it...?

P: Yea. Really ehm, I suppose if I link back to the guys that we are supporting.

R: Yeah, those same guys that are so able.

P: The guys that we're supporting that are able? Yeah, we're only there really to kind of help them with different... So, one of the guys... He has a job. He wants to change career. He's not enjoying his [current job] ... with him autism as well there's a bit of difficulty with, there's a bit of friction going on with his manager and he's keen to get out. And he will come to you and say will you help me, you know maybe like doing up a CV, things like that. But then he will come and he will change his mind as well. And say oh no things are actually going OK again at work.

R: OK.

P: 'I'm not ready to do anything'. You know, I think a lot of the lads they're not really good with change or moving on to some other stuff. So, I'm really there as a, you know to talk things out. Well what we will do is independent living skills would be a big thing you know. So, the guys who are living out in the community, we would help to source them a place to live first of all, you know maybe contacting landlords and going to viewings.

R: Really.

P: And speaking on their behalf because they wouldn't really have the skills maybe to do that themselves. Then we would also, you know, link in with getting maybe like once they've got a place to live is to get them like, get them rent allowance, kind of linking in with the community that way. Setting up bank direct debits, you know...

R: All of that.

P: That kind of stuff. And then into the kind of I suppose day to day managing a place to live, that kind of cleaning, cooking, you know setting up direct debits for bills and utilities you know that kind of thing. But you know to be fair, that's been done for most of the lad's a while ago now. But really when you do meet up with them it's kind of more functional I would say. It's kind of gone, as I would have said, a little bit of stagnation there. Like one of the guys, the guy who XXX, it's very hard to meet up with him.

R: He's so busy?

P: He's busy yea. Well he works four or five days a week anyway. And he's working XXX and he's living XXX so he commutes, so he's gone, all day yeah. And when he does get

home he goes to the gym in the evening. So we might have a time set up with him to meet, but he'll cancel. You know. So, they're quite self-sufficient. You know.

R: Yes they are.

P: Yeah like there's one of the guys, they really just want you to kind of you know get a lift to the supermarket because they want to get a weekly shop in, but they don't drive. So, literally, drive to the supermarket, off you go.

R: Yeah. So, they very much are independent people and you really are just supporting them in that transition into that life, getting the accommodation and then with the practicalities.

P: Yea those guys. And then there are other guys who...

R: The overnighters.

P: Yea. They're a little bit more, I won't say complex, but, with two of them it's quite functional. They don't really want you to be...

R: Have a chat...

P: ...working on hobbies. Ah well no they'll have a chat as well yeah but to work on hobbies and goals and all that. The guys are like 'don't be talking to me about this', like.

R: They're sorted?

P: Ugh, I don't know is it that they're sorted. It's a bit of, eh, I suppose I don't know if I was being kind of critical, would say they've probably been mammy'd a bit, and to go working on goals, that just seems like effort like. Do you know what I mean, and it's like, no I don't want to know about any of that stuff you know I'll do my own thing. So, in that sense, it's tricky like you have to be kind of creative where possible.

R: So, this is kind of, because the people you're with now are so capable you don't really have to do the, you don't really have to support them in communicating their needs?

P: No.

R: They can communicate their own needs.

P: Yea.

R: Do you have to support them in social interaction or engagement?

P: Eh so in that sense now, with other people in the community?

R: Yea.

P: Sometimes yea.

R: Yea there'd be a bit of that.

P: Yea.

R: And then you don't have to support them during meal times?

P: Eh, well we have to cook, I have to cook for two of them we would cook for yeah. They're not, they don't cook. One of the guys will, like they're able to use a microwave and all that to you know put something into the microwave and heat it up. But so far as cooking a meal, they don't cook. Or, they're in the process of...

R: Thinking about it...

P: Well, I suppose one of the guys ... is with the service years ... XXXXXX ... he's a tricky one to kind of work on stuff like that with, because he really doesn't want to do, anything. Like I'd say it was the case that a lot of it was done for him. So that's, that's tricky. And we have been kind of, because he's quite new to us, during the summer another service user came on board with us as well, and there was extra staff brought in, so now this service user could get 10 to 12 staff seeing him throughout the course of a week. So, he's not getting, you know he's not getting any kind of structure. Its all a bit... higgledy-piggledy, you know. But I'm just after coming from a meeting there... so it sounds like yea 2018, kind of reset...

R: Reset.

P: Different, like just looking at things a lot differently you know. With the idea being, like our whole, like you know, so there those service users that I mentioned they fall under HIQA. So, an inspector will come out and have come out and inspected the supports that they get and all that.

R: So, what push would that put, the HIQA push, on how you do things differently. I'm sure HIQA's happy but...

P: Well the idea would be that they wouldn't be under HIQA that they would become self-sufficient, you know.

R: Really wow. Yea just people.

P: More autonomous. That's the goal. We're a while away from that.

R: That's an interesting shift isn't it? So, they'd be people having supports, social supports.

P: I was even thinking that myself when [new management] came in and said this is what I want. And we're going 'oh right'... yea that's very interesting.

R: So, this is very interesting that we have this conversation now, because you're able to think about how, maybe that person who has maybe 12 people coming during the week and then actually, as you say, kind of mammying.

P: Yea now that's all being...

R: Looked at differently, going forward.

P: Oh, it is yeah. There's going to be a change in rosters and it's going to whittle it down to maybe 5 people seeing him throughout the week.

R: So, then that'll be the relationship building and the getting to know and encouraging goal setting and...

P: Boundaries is a big thing as well.

R: Really.

P: Yeah yeah definitely, yeah, boundaries is huge. Like, if you kind of go in on shift, one on one, with XXX you have to have your boundaries up you know, they will railroad you, like...

R: Yep.

P: Yeah, definitely, like. And if I come in to work say and I'm in good form, myself you know, all is well with me in the world, I can have a good few hours with the lads you know. Whereas if I'm coming in a bit stressed, it can be, it's like as if they sense it, yeah it can be tough, it can be a tough few hours, for sure.

R: So, that kind of brings us onto the other questions of...

P: Sorry I'm probably jumping all over the place.

R: No no, because your people are different, from say somebody else's people. This brings us down to the bit now about, what do you actually have to put in your head before you go in to them. So, you've said now you'd want to be in good form and you'd want to mind your boundaries. So, particularly with those sort of people who are very capable, ehm, how do you prepare yourself, so what would you be saying to yourself beforehand, like how do you press the 'I'm at work' button? Because it's an internal thing isn't it?

P: Oh, it is yeah. It's very much an individual thing. Now, I would like our team, we would lean on each other quite a bit, I suppose for peer to peer support, you know. I'd look at it just as common sense, you know. Where, possible, you know if you're feeling a bit stressed your own common sense goes out the window a bit as well. You can end up in a kind of, an argument or, going down the rabbit hole a little bit with the lads. You know, they are autistic as well, and it's that kind of, you know thinking. So, the thing is, I'm quite good at, I suppose I've known one of the guys since I've started to work here. The other guy, he's very sociable, so they're able to communicate to you like I don't like this, or I do like this. A couple of times if you're trying to kind of guide things along into doing something, you know, bring down your laundry and put a wash of clothes on, or you know that kind of way, which they're able to do. And they're just like, 'no, I won't do that, that's not my job'. Yea.

R: They don't think it's their job?

P: Yea well one of the guys actually says, 'well I don't want to do this with you, I'll wait until XXX staff comes in. I'll do it with XXX staff'.

R: Yeah?

P: This is all stuff that's sort of happened where boundaries were kind of you know, not adhered to.

R: Yea.

P: I've been guilty of it as well, you know, because sometimes in your head you're just like, 'I just want to get through this next few hours, I'd nearly do it myself', you know. And that's my own...

R: Well, that's the point actually, that's the kind of thinking that we're looking for. If you go in there, and the people have an idea of what you should be doing, they want you to do something. But you have an idea kind of about what should be happening. That's the bit then, how do you...

P: This is...

R: And then it's meant to be person centred... So, what does that actually mean? 'I'm waiting for this staff to do my laundry', is it we go with it because it's person centred? Or, do we stop and look at that differently? They're big questions.

P: They are huge questions.

R: This person-centred stuff is great craic.

P: As I was looking at the questions, I was there going 'what the hell...', I'm going to have to...

R: Think about that?

P: I do have to think about it yeah. There's a lot of eh, I would say from my own personal, when I first started here, I was much better at, kind of, self-reflecting, you know kind of...

R: That's the word.

P: And I think over a period of time, you get used to things.

R: You do.

P: Certain kind of, it just becomes a bit more, stagnant, day to day. And you kind of forget, OK, jez I need to be self-reflecting here a bit more. You know. Because it actually happened with another service user last week from a different team. XXXXX. Straight away, we slipped into 'service user – staff'. And it was only afterwards, someone pointed it out to me, he was a bit scruffy coming in or XXX. And you kind of think on it going, a lot of it was really my fault. XXXXX. And we did then the next day we had a bit of a chat, and I had never actually spoken to anyone before about how they dress. You know it was that

kind of critical thing so it was different for me to do that. Ehm, I'm going well off topic here.

R: No, you're not. And what I'm asking really is what's in your head. And what's in your head is, there's washing to be done, I want to get through my few hours, but actually there's meant to be another agenda, and then there's the bit you started off talking about boundaries.

P: Yea.

R: So, it is an interpersonal interaction. There's people in the service for years who have a certain expectation. Now you have someone coming in with a different view so we actually think the service might actually going to be mixing that whole thing up again.

P: Yea.

R: And you'll be walking in to people who have an expectation, I'm saying calling the shots, in a particular way.

P: I would say, master – servant.

R: Master – servant. So, and yet, and yet, it's meant to be the person-centred stuff. Has that really been teased out, because that's really complicated. You're not a servant. And neither are they masters. And this person centred, the collaborative word would be the word we'd use, you know, there's two people in this. You serve... It's very interesting, with such capable people.

P: Yea, well what I've found, since I've started working here, I've never worked on a person-centred plan. Not one.

R: Oh really. And isn't it all the rage? It's meant to be the rage.

P: Well, I...

R: Does HIQA not have...

P: Well, for the guys that fall under HIQA, they have a support plan which is a much meatier document. It kind of covers everything. As in like if you were to just go in, and all of us had rang in sick, but you were called to come in and work with one of the lads.

R: Yes.

P: There's literally like a big folder because there's no one here to tell me what to do. To go, right, here's his social care needs, and his health needs as well you know.

R: Yes, of course.

P: And that's, and his daily routine and what have you. It's all kind of in there.

R: So, that's what that is.

P: But, it's a very meaty folder which it constantly changes as well, so it's kind of hard to keep up with. But with the PCP, I went back to college to do social care, and they were

talking about PCP's, and there is PCP's, I've seen them in the press over there. And kind of when I started here, I was told oh we're actually moving away from PCP's. more like support plan, sort of, and now lately I'm hearing OK we're back to PCP's again. But, I've never actually sat down and worked on a PCP. So, I've done, sat down and done goals and what have you, but not a PCP kind of format.

R: Now it's interesting, because you work with the very able people, and its boundaries. That's relationships.

P: Yea.

R: And you put autism into that. And then you can see how maybe, the needs are, as you say, more to do with, relationships.

P: Yeah, yeah. Yeah. I would agree. Yeah.

R: As humans. As citizens. As autonomous beings. The slave-master thing, isn't really healthy in a democracy.

P: Yeah, well I wouldn't say slave master, more...

R: You're the cleaner?

P: You're the mammy. Do you know, there's a bit of that, for sure. Now also as well as that, I would say, like that they'll come to you as well like you know what I mean. <Yeah, yeah, yeah>. You know since like... <you're the mammy bit there>. Yeah. The trust is there. <The emotional, yeah>.

R: Yeah.

P: So, in that sense, like you know <Right> they will come to you and they'll talk about kind of stuff that's bothering them, or sometimes maybe something another staff member might have said to them. You know.

R: Right.

P: Ehm, generally it's just, you know, it's them getting the hump about something. But, eh, you know like, one of the guys, he'll come and he'll talk about sexuality quite a bit you know, and ehm, and the way he sort of views sexuality, and then kind of like society, the way it's supposed to be in society. And it's, you know it's his autism as well, kind of all thrown in there. So, bits like that I probably wouldn't be that experienced with, but I kind of just use sort of common sense, where possible you know.

R: Yeah, it's the common sense but then yeah, but your <but you do, tricky, you veer into tricky... > Yeah that's what I'm saying, you go in each day and you do need to have some kind of button pressed around how you're going to be, in the session.

P: Yes. Yeah. Well, sometimes something might come up that'll even be like there's some sort of like a bang like going oh shit this is, like eh reminding me of something in my personal life. Eh, I've had that a couple of times. <Yeah>. Eh, you know.

R: So, you guys then as peers, you'd have a chat?

P: We would.

R: And you have a structure?

P: We have, it's really informal. Literally, we just chat amongst ourselves. You know.

R: So, you don't have a...

P: We have supervision, I think, 4 times a year, is it, yeah, I think it's 4 times a year.

R: Ok, every 3 months?

P: Every three months, but I couldn't tell ya what we talked about in my last supervision. <Yeah>. A little bit, if you know what I mean.

R: I do. Yeah.

P: I find that its more of a tick the box, kind of thing. I find more talking amongst my colleagues, teasing stuff out <yeah> much more beneficial. And that's not against, anything against the [person] who's doing the supervision.

R: No, no. it's the nature of what your talking about actually is something, like you were using the word reflect, kinda ya learn when you talk to other people, you hear yourself, and then you think about it, and then you...

P: Well, even an outside person, like actually it was XXX who said it to me last week about the XXX who came in, and oh you know maybe you should say about XXXX. And I was kind of oh yeah I didn't pick up on that because I was concentrating on, straight away going, some part of my brain was saying XXX, as opposed to XXX. You know, so.

R: Yeah.

P: Yeah. So, I've definitely found that my own ability to self-reflect has dipped the last two years anyway. It's kind of like, now that we're having a lot of change, you know in our team the way it's going to be run for 2018, its, I need to get back into it. It's kind of one of the reasons I agreed to do this as well, you know.

R: And, what's interesting about the questions, is ehm, really thinking is there anything that would help? So, the nature of your thinking and the nature of how you approach your job, and we've just talked about, you talk to peers <Hmm>, and that seems to be, helpful?

P: Yeah.

R: Could you think that could be looked at, more?

P: Peer support?

R: Yeah. More, as a...

P: Instead of supervision? Is it or...?

R: Not necessarily instead of, but maybe more structured in addition?

P: Well, yeah, we do talk about it say at our monthly team meeting.

R: A monthly meeting, yeah.

P: But the team has got much bigger in the last year.

R: Ok.

P: And it's become, kind of like, you know to sit down and everyone reflect on, you know <you won't yeah> peer to peer support, the meeting kind of loses it's structure.

R: Of course. Yeah.

P: You know, like I, I literally, that was our meeting there earlier on, I left at one o'clock, it started at around quarter to eleven.

R: Oh come on.

P: And it's still going, probably, you know. <Yeah, yeah>. So, I don't know about that, ehm.

R: So, would it be something to think about, what would help? Would there be anything that would help, in <yeah> you being able to do the support, that well, not saying that you're not doing the support, but you thinking about the support that you're giving so that you can keep doing a good job?

P: Yeah... well, I suppose if we, we are making, we're kind of splitting the teams into two.

R: Yeah.

P: Although it's still going to be all one big team, <Hmm>, but it's like split into two, in that sense you would be kind of hoping that it's more structured and you can kinda work as one.

R: Yeah.

P: All working as one together <yeah> eh, <yeah>, part of the problem was a lot of people who were kinda, the last year it's kind of gone, everyone kind of running with the ball one way <yeah>, you know, and <yeah>, so I think yeah definitely like a smaller team. Like a big team doesn't work.

R: Yeah.

P: It helps to work with a smaller team.

R: Yeah.

P: A bit of it, it's kind of, it's just like rapport that you kind of build up amongst colleagues yourselves, you know. Because we had a kind of a very tight team, it was smaller, and kind of you know the last year, you know XXX people started <it's a lot> yeah on top of

that. So, you're, you're, they're coming to you for guidance, whereas, I don't know if I necessarily am the person to be giving the guidance. Not that I <yeah>, you know, eh <Yeah>. I would say there's a bit of a problem with the leadership, <yeah>, in that sense, if you know what I mean?

R: I do.

P: I'm only kind of coming to this kind of idea here myself.

R: Yeah. There's actually flux, there's stuff happening now. Yeah.

P: Yeah. There's stuff, yeah, and it remains to be seen how that will turn out.

R: Yeah.

P: Because I have seen stuff kind of worked on before, a few bits here and there talked about, and it kind of came to nothing.

R: Yeah.

P: So, I'd eh, I'd hold my breathe on it, a little bit.

R: Yeah.

P: Yeah. But you know, I'm cautiously optimistic.

R: Yeah. So, just to check if there's anything I've missed, eh. What sort of planning do you have to do when you go to visit the people? Do you have to do much planning?

P: Oh right, so the guys we're visiting <your regular crew> out in the community?

R: Yeah.

P: Yeah, eh. It depends, yeah I mean the guys who are out in the community living on their own, generally you'd give them a text or a call <OK> earlier on that day, 'are you still on to meet up today?', or whatever, 'do you, is there anything you fancy doing?', or 'is there anything planned to do?', and they would generally get back, you know. Eh, and it's usually quite functional stuff, you know.

R: So, it would be planning, day to day?

P: With the guys in the house, it is planning, eh, day to day, yeah. We'd like, say on a Sunday we'd get an email sent out for like a roster for the week <Hmm> ahead, so there'd be certain like stuff you would have to do throughout the week, but that's more kind of for the staff, <yeah yeah> the service users wouldn't really be <yeah> involved in that. But, eh, yeah it's not really done kind of like day to day, the guys, we're kind of there. The guys that are in the houses <yeah>, that we're in with, we're kind of more there, I would say, I kind of anyway am more there in the background.

R: Yeah.

P: Kind of like tipping away, doing a few bits <yeah> in the background.

R: Yeah.

P: And, they'll come to me, generally. That's the way it kind of is.

R: Yeah. So, that's how you, that's the amount of planning, would be the text, the meeting up <yeah>, and you get there.

P: I suppose, I'm kind of, maybe I'm confusing you a little bit there, because there's I suppose there's two kind of groups of service users. The guys that are out in the community they're living on their own <OK and then the ones who you're 24hrs with, there's things to be done>. There's things to do yeah there would be like daily stuff to be done <Right> yeah. You would try, what I would try to do is do it in a really casual manner like, because the lads generally don't want to be kind of, you know it's their house as well, so I respect that, but they don't, they're not really into sitting down and doing goals and objectives <yeah> and kind of what they want from their lives in a kind of, in a normal kind of manner.

R: Yeah.

P: You know. Now, XXX was saying that they've got some plans for next year, like, kind of life maps <yes> and stuff like that, that we have never worked on with the guys. So, that sounds interesting. <Yeah>. So, we'll see how that kind of pans out <yeah>. But for the normal day to day stuff, it really is, you come in, you have a list of jobs to do, kind of as staff <yeah>, checks and what have you <yeah>. And, with the lads, with the guys then I might just say something like you know, 'we might just load the dishwasher' but I'll do it in a very casual kind of way, <Hmm> or, 'do you want to empty the dishwasher while we're chatting' kind of thing, and it's kind of just done like that. And I'll just be kind of taking a note of it when I'm kind of <yeah> doing my reports, you know it's part <yeah yeah> of their kind of, you know their independent living skills, you know.

R: Yeah.

P: That's kind of it <yeah yeah>. But it, you can see how it's kind of gone a bit stagnant <yeah yeah> over the past two years I'd say anyway you know.

R: Yeah.

P: It's just very kind of functional.

R: Yeah. So, how do you know that the people you're with are actually happy with your support?

P: With mine individually, or?

R: Yeah, with your person, like, how would you kind of.

P: Well, I would have a good rapport with them.

R: Yeah.

P: Ehm I would find that ehm, like they'll generally tell me <let you know>, yeah, yeah, yeah. I've had a couple of incidences, incidents even in the last two weeks, you know ehm, where I've annoyed them, you know. Ehm, but that's, that's life <yeah> there's, <they'll just tell you>, it's a relationship, you know.

R: Yeah.

P: Some days you're the best ever, and another day then you're, you're an asshole like, you know.

R: Hmm, they just tell ya.

P: Yeah, the guys are well able to tell me yeah.

R: Yeah. Yeah.

P: Like, I hope they're telling me anyway!

R: Well, they seem really capable, and then some of the people are part of XXX wouldn't be that capable.

P: Yeah yeah there would be a lot more, yeah in some of the house XXX yeah there'd be <hard to know>. It'd be hard to know yeah. I haven't worked with any of the guys there.

R: Yeah.

P: So, I wouldn't really know, yeah the nuances of that kind of work.

R: Exactly.

P: But, I'm not bad, I'd like to think I'm not bad at the, the working with the higher functioning guys like you know.

R: Yeah. And, they give you feedback. Is there ever a chance where you ask people for feedback? [Long pause]. Would there be a kind of a formal way of?

P: There is a, well I mean, they, they can, there there there is the the eh, if they want to make a complaint.

R: Hmm, but I mean just a general satisfaction survey kind of thing?

P: Eh, for the service users? I'm trying to think. Do you know, I actually don't know? I'd have to get back to ya.

R: No no. I just was wondering, yeah.

P: There could well be. There could well be.

R: Yeah.

P: I know if there is an issue around where they kind of feel like they want to make a complaint <yeah there's procedure> or if there's safeguarding, there is kind of you know in their houses there is like you know like a poster up on the wall <Hmmm> you know like a service user friendly one. Then it also falls into the bit going, well if that was in my home I wouldn't be having this kind of stuff up, you know, but.

R: It's probably HIQA though is it?

P: Oh, it's all HIQA yeah yeah yeah. It is all HIQA yeah <yeah>. So, that, that is hopefully the plan going forward that the guys will kind of not come under the HIQA radar <yeah>. You know that they're becoming more autonomous <Hmm>. Now, that also falls into the thing where the more autonomous they become, the less mammying is needed. You know, the mammying will have to stop, you know what I mean, so eh whether they want to give up the, because they're not happy about having their houses, you know, being inspected by HIQA, or having like you know their kitchen looking like an office with folders and all that there you know. But, also, they like, they definitely like to be driven around and <yep> you know, get this for me, get that for me. That kinda thing. Eh, it's something I need to kinda, yeah I do need to reflect on a bit more, because I have fallen, really easily fallen into that <yeah yeah> the mammying role.

R: Yeah well, it's understandable.

P: Yeah.

R: If the leadership isn't looking for something different.

P: Well by all accounts it sounds like that is a bit of a change <yeah> you know. That there will be a bit more, there'll be a bit more kind of eh, expectations on me, like, to go, OK what am I doing here, you know. Which is good <yeah> which is good. You know. Except for the days when I'm really really stressed. Because then it's just much easier just to do it, you know <of course it is!>, or else just get into this kind of battle, because the lads will battle you like.

R: Yes.

P: They're not going to give, you know, like they'll dig the heels in.

R: That'll be interesting to figure that out now.

P: Well, you have to do it subtly. Like, it has to be subtly. You know you have to be at your own, kinda you have to be thinking kind of clear headed yourself, to be going in with a subtle kind of approach.

R: That's that's the point, yeah!

P: I have gone in, ehm, barging in kind of 'whhaaa' I need you to do that, kind of and it's just been <it doesn't work> a disaster. It escalates, <it does>, very quickly yeah. So, I have, I've made that mistake, and I'll probably make that mistake again.

R: Of course you will, we all do yeah.

P: So, I find that, yeah, definitely, the less stressed you are, the easier it is.

R: Yeah. So, that's the deep breathe before you go in.

P: The deep breaths, even just managing yourself outside of work, you know <Hmm>.

R: Clear the head.

P: Yeah just like, exercise, eating well. Stuff that I can be good at for periods of time, so, yeah.

R: So that's important, and the other thing I picked up was this idea of being able to have your peer group to help with the debrief or the reflection.

P: Anything I've ever really learned, while working in social care, it's with, from my peer to peer colleagues. Just, informal chatting. You know.

R: Because they get the context.

P: They're the ones that really know.

R: Yeah, they get it.

P: They're the frontline, same as you like.

R: Yeah, and they have a perspective and it might be different and that helps you.

P: Yeah yeah absolutely. Do you know, some guys, some people are just good at thinking a bit more outside the box, or I might be a bit more regimented and that might work in some aspects and it really is, eh what's the word, it's a dance isn't it the whole thing.

R: It is, yeah, it is a dance you're right yeah. Yeah well listen that's all our questions and what we are interested in is the thinking, and you see your service, your service users are different to, say somebody else's, and then it's as you say now with this change coming, this was planned before there was going to be this change.

P: Yea.

R: So, it's very interesting that you've just had a meeting today.

P: Literally yeah yeah yeah.

R: If we talked to you yesterday it would have been different.

P: Yea yea yeah, no I would have been a bit more, ehm, pessimistic. Not pessimistic, but just kind of. No I was, I was pleasantly surprised with some of the ideas that are proposed, you know. Again, I'd wait cautiously.

R: Wait and see. Yeah.

P: You know. Sometimes, in my own experience, working in XXX <big corporate stuff> the manager, yeah, when a manager comes in and has got all these ideas but the, the eh, it's, it's all waffle, a lot of the time, do you know.

R: Yep. To make change, it's not just people with autism.

P: They they've got the job for being able to sell something you know. They might try it for a while and you know. Then it's just dropped and never mentioned again, you know that kind of way?

R: Yeah.

P: 'Oh I wonder whatever happened about that thing?' 'Ohh, I don't know what you're talking about?'

R: Yeah.

P: You know. Yeah. A lot of that. But, no I think this is much more rewarding and enjoyable work than what I had done say working for XXX. You know, eh definitely like yeah it's been a pleasure actually do you know. Because you are working with guys that are kind of, I say guys, it's all males that <yeah> we support on our team. But eh, you know they are kind of reclusive characters you know, living out there. They don't really like some of them don't really like engage fully with the way society expects the rest of the population to do, so they're kind of out there. So, it is a privilege to be kind of be in, you know, to get to know them and kind of be welcomed into their kind of their homes, you know, build a relationship, fight, get on well, you know. All that.

R: It's real.

P: It is real, yeah yeah yeah. It's good practice, I suppose, for having kids and all that kind of stuff.

R: Yeah yeah it's real.

P: It's all relevant you know.

R: People people.

P: Yeah, yeah, so.

R: Well listen thanks, and we are delighted, well I'm delighted.

P: Are you sure you've...

R: It was all that thinking stuff around thinking before you go in and how you manage and for you guys it's the relationship and the boundaries with the people at the level you're at. And, whereas with others there would be a lot more of the kind of practical you know understanding their communication needs, or their sensory needs, or yeah.

P: Yeah well the lads would have sensory needs as well you know. I didn't really get into that, I kind of went off on a tangent <yeah>. But yeah there would be sensory issues around a couple of them you know.

R: And they'd be aware themselves, would they?

P: They're quite good, yeah yeah. They would be ehm, yeah well I mean, there's one guy in particular, he's complicated like, yeah he's complicated. He would be aware of kinda if he's about to get into a meltdown, you know, and other guys they're not as good. Like, even guys who are living out in the community, versus one or two of the guys who fall under HIQA. The guy who falls under HIQA is good at going, 'ok I'm actually having a meltdown here, I'm just going to go to my bedroom'.

R: Wow.

P: 'And I'm going to stay there for a few hours'. That's it, whereas one of the guys out in the community, he's not able to self-regulate at all, you know, he is just going up and up and up and up and up. And we've had issues where there's new staff coming in and they're not knowing, they're not seeing the kind of warning signs, you know, that someone's kind of getting out of control and they're kind of nearly feeding into it a bit and its all kind of messy.

R: Really?

P: Ah we've had a bit of that yeah. Sorry, we've had a bit of that but you kind of have to. Sometimes you have to kind of have that to happen to you to kind of..

R: Yeah, notice.

P: For you to kind of learn really like, it's kind of nearly like,

R: And what would you do then with that particular person, you see they're

P: Yeah well, that particular person, again from, from, working with, from peer to peer support from the colleagues, the one to one stuff we all would be going 'OK, what works to get him to chill out', you know, keeping it light.

R: Really?

P: Humorous, kind of bullshitting a bit with him as well, kind of going 'it's going to be OK, we're all behind you, we're all there, doing the best', all that kind of stuff.

R: Yeah.

P: It really works with him. And he'll switch off straight away.

R: Really.

P: It's just back to normal yeah. It's just kind of stuff we've figured out.

R: Yeah and that's your peer to peer.

P: I could be telling him lies, and sometimes I am telling him lies <yeah, we're all behind you>, I do tell white lies, it's kind of. I know it's about making the lads autonomous and all that but sometimes you sort of need to tell the <it's support> few porkies, you know if it kind of brings down their stress levels, or kind of makes things a bit more manageable.

R: and you'd pick that up from your

P: I would have always picked it up from peer to peer, ah well like my line manager would have known this stuff as well like, but it is generally we kind of toss it out amongst ourselves. We don't really, like any kind of stuff that we've done with the clinical support <yeah>, it, it, you know, it was 'well that's just autism', like there was a lot of that.

R: So?

P: So, we would have had a clinical psychologist, XXX, but a couple of times I've kind of been in meetings with them about issues the lads would be having, and eh it was generally always just like 'aw that's just autism'. Kind of, as opposed to.

R: Well what do we do now? What would be helpful?

P: Yeah yeah there was a bit of that. Yeah so, in some instances they were probably right, you know, sometimes it is just autism. It is just part of the presentation. But eh, you kind of found yourself in there having to fight it out a bit, not fight it out, I can't think of the word, but kind of, you have to go in there prepared anyway, yeah. Give rationales, plenty of rational to kinda get some support. But generally, I've always found peer to peer stuff was much more successful.

R: Yep.

P: Yeah.

R: Yep.

P: Yeah, so that's. Whereas I, yeah it's interesting though if we could make it more of a formal thing, the peer to peer stuff.

R: Yeah. And recognise it as really valuable for the kind of work you do <yeah>, with your people. Might need that support, particularly around the boundaries and the relationships, that could be. And other people want, maybe with different service users, might want different kind of support.

P: Yeah. I dunno, yeah. I suppose maybe if it's a smaller team, peer to peer stuff. Like I find just chatting casually, as opposed to having it written down somewhere, <yeah> it nearly works better, if you know what I mean.

R: Yeah.

P: Ehm, so I duno if the formal thing, kinda would work?

R: Hmm.

P: Do you know if I was to sit down and I'm reading this kind of say support plan, duh duh duh, which I do as well <yeah>. Now, it does help, like it does help guide you. I think it's more of a guide, you know in the initial stages as you're trying to get to know a service user. Whereas when you both know each other, and you're working in the day to day kind of stuff, its, I find I'll always kind of find myself leaning back on my colleagues, and them with me as well, you know. It works. It works quite well, you know. It's a solid kind of group you know. So. Maybe that's just the culture that we have in our team <Hmm>.

So, yeah. I don't know.

R: Yeah. Well listen thanks again.

P: No worries.

Transcript Six

R: So, other than that, what we're really interested in is what's in your head when you're trying to support people?

P: Ok

R: And a good place we found to start is to say, when you start coming to work, how do you prepare yourself, for coming in to work?

P: So

R: How do you prepare your head?

P: So, coming in to work. So, obviously you think about kinda, what the lads, kinda, cause we would have ehm timetables which the lads have kinda scheduled out. So, you'd kinda know briefly, like, if the lads want to change their mind, they're entitled to change their mind.

R: Hmm.

P: So, for preparing today, you'd kinda say, Ok. Like I know with one service user like, if the weather is quite bad, you're kind of expecting to have a not so great day.

R: Yeah.

P: Because the weather would really affect him. So, if it's raining, then you just kind of prepare yourself

R: For the bad form, yeah

P: Yeah

R: Yeah, exactly. Exactly.

P: Yeah?

R: So, you know someone well to know, he's not going to be in good form.

P: Yeah.

R: Yeah. So, you have a timetable, you have a schedule, but.

P: So, basically then, you're preparing yourself for the activities of what, kind of, before I'd go to work anyway I'd think ok so what service users I'd kinda be supporting. Like, I'd kind of have a rough estimate of what's going on throughout the day. Ehm, and then, again, if it's due to the weather, like we wouldn't be able to do that. And then with public transport and stuff like that. So, you're just kinda going through the day and what you're going to do.

R: Hmm. So, you're in work now, and you're with somebody and could you tell us a bit more about how you'd support them say, in their communication? How would you know if they're letting you know what they want to do?

P: Ehm, our lads would be quite vocal.

R: So, they can say

P: Yeah, they are very, ehm, the six lads that I personally work with, are very, are all verbal.

R: Hmm.

P: Ehm, with direct communication, like maybe you could see if, ehm like for one service user, if he's kind of a little bit snappy, a little bit out of sorts, then that's how we would kind of know if there's something up. And then we'd sit down and we'd have a chat about it. But, one service user, he's actually having a bit of a stressful time at the minute. But he's very vocal and he's able to express himself.

R: So, you really don't have to do much listening, or you do?

P: Oh, I'm listening yeah.

R: You would do a lot of listening?

P: Yeah.

R: Ok. So, then how do people let you know what they want to do with the time table or with the activities? How would they let you know?

P: So, we do like a Voice and Choice every week.

R: Ah, ok. Right.

P: So, it's kind of like a meeting of like, voices, choices.

R: Yeah

P: So, they would come down and kinda express. We'd ask how do you think your timetable is going? And, is there anything that you would like to do? Like a one to one day. And, so, that's how they'd normally get their voice across. And then, like if the lads don't want to do an activity, they'll let you know they don't want to do the activity.

R: Really yeah.

P: Yeah.

R: Yeah yeah yeah. So, they sound really capable?

P: Yeah. They would be very capable, but again ehm, they would be quite low functioning as well.

R: Right

P: Eh, in the sense of comprehension.

R: Ok, yeah.

P: Ehm, levels would be, ehm and any kind of sudden change very quickly, can really distress the lads. And, they can become quite upset.

R: Hmm

P: So, there would be a lot of support in that kind of

R: And how would you do that then?

P: Ehm, for example, one service user, we were doing his shop training, and that's, he goes to Aldi, gets his basket and I'm just kind of shadowing. And he'd get all his groceries and so he had a trolley bag, and a bag, ehm, and we were on the bus. So, the bus had like a sudden jerk, so he kind of moved forward, and he got an, obviously a fright.

R: Hmm

P: And he expressed himself by using really bad language, and shouting and quite, screaming. Because it was just a sudden movement, he genuinely got a fright. Whereas, you know, we could, if we got a fright we might just say, 'oh'. But you know, this for him was an awful big fright and he didn't know what way to manage it.

R: Hmm

P: So, supporting there, we were getting off the bus, I was like 'it's ok, let's breathe, we'll get off the buses, and he did apologise though to the bus driver

R: Yeah

P: Which was really good.

R: Yeah

P: Ehm, and then just kind of have deep breaths, and then what way we should maybe carry, or hold the pole, instead of kind of just balancing,

R: Having the two bags and

P: And maybe we could move the bag up around where our wrist is, or we could put it over where there's like a little basket kind of to put it in to.

R: Yeah, yeah, yeah. Yeah.

P: You know. So, it's life learning as well for me, like you know, to kind of reflect like and say, oh well I should have said, you know, 'oh you could move your bag down'. Because he wasn't quite holding it he just had his hand there like on it.

R: Hmm.

P: So

R: So, you'd be thinking about next time, what would you be thinking?

P: Yeah next time. So, I'd be like, ok, so that happened that time

R: Yeah

P: Learn from it and then maybe we could put the bag over where there's like a little bag place

R: Yep

P: Or, to wait when you have the trolley bag and the bag, to just wait. And, wait till the bus stops, and then proceed to go, off the bus.

R: Yeah. So, then that's say in communicating in daily activities. In, so they're able to tell you what their hobbies and interests are?

P: Ehm, yeah like from what I, like, they would, like they'll say what they like, and what they don't like.

R: Yeah. And, do you have to give a lot of choices for people to get ideas, or do they have ideas themselves?

P: Our lads would have, ehm. Like, one service user would be very, he would know exactly what he wants.

R: Yes

P: You know, he would be very adamant of, so trying to kind of bring in new activities into his schedule. And to try to open his mind up as well, because I think as well with autism, it's very, there's a very routine. And, there's kind of, they need to get those kind of choices in to build on their interests

R: Yeah. Yeah.

P: And hobbies. Otherwise they'd stick to the same thing

R: They would

P: For the rest of their lives

R: Hmm. So, how do you do that?

P: Ehm, well, one example, ehm, one of our service users wanted to lose weight, and ehm, he was going through kind of healthy eating. So, I suggested slimming world. And I kind of gave him the brief map of to what slimming world was, and we went through it we sat down together, we looked at it the computer. Ehm, to see would he be interested. I explained, because I was personally in it before, so I was kind of explaining what way the group would be, and that we'd listen to others and that it's not a diet, it's a food optimising.

R: Hmm

P: And so, this was completely new to him. And ehm, he was really interested in doing it. Ehm, so he went with it and he absolutely loves it now.

R: Really?

P: Loves it. Loves going every week. He's like eh down three stone.

R: Awh!

P: Like he has really stuck to it. And it's not that it's like a diet for him, it's a complete food optimising

R: A way of looking at food

P: Yeah. Like he's started to look at eating so much fruit now in the mornings, whereas he would never have eaten fruit before.

R: Yeah

P: Or, like his breakfast would have been, like his daily intake would be in the morning have two slices of toast, ehm, a salad or lunch with a slice of bread, and then at home dinner and a snack. Whereas now he's having like a big bowl of fruit and in the evenings, he's then having his lunch, and he's having, he's making all his own lunch

R: Oh, my goodness

P: With support

R: Yeah yeah yeah

P: Ehm, but he's doing fantastic. And he's like, since he's gone to the group, it's really nice to see because it's really community based, and before when he first started, people weren't really too sure what way to approach him.

R: Yeah

P: So, they were you know, kind of, oh you know the big smiles that everyone kind of does, ehm, to now, 'oh hey how are you, awe how did you do this week?'. And like he's won awards now for eh Mr. Sleek of 2017.

R: Oh my god.

P: Cause everyone voted for him because they thought he was very inspirational to the class. And not just because of his disability, because of all the weight he lost. Like the disability is not seen, at all. Which is brilliant.

R: Hmm. And did you have to support him much to start there?

P: Yeah, we supported. Ehm with that typical service user we have ehm, boundaries would be very good, for him. Or, a lot of inappropriate kind of behaviour of wanting to see ehm, maybe tongues and stuff like that. Ehm, so we'd do him a social story.

R: Ahah.

P: So, our social story is our kind of, way of going out into the community to reduce that for a lot of our service users.

R: Right, right. So, you have a social story. You did a social story then for him going to his,

P: Yeah so there'd be a social story of 'out in the community'. And ehm, 'what way we act', cause he loves cars. Really really loves cars and would, you know kind of go up very closely to look in. whereas someone might get the wrong idea, that he's looking in

R: Horrible, yeah

P: So, that's a, we just kind of said, maybe when we go out, we don't look into the cars. Maybe we could have a, just keep walking and you look after yourself and mind yourself as you're walking down. So, it's to kind of put the focus in on himself and be aware more of say the roads, and road safety and stuff like that.

R: Hmm. Right, and then to get him to slimming world, did you accompany him and bring him there the first time?

P: Yeah, so we, he still now is accompanied ehm, from, by us. So, he still goes to a slimming world group, but ehm, yeah no so we'd go and do our normal routine for that would be we'd go on the bus out to Aldi in XXX, and he'd go then and he'd get all his groceries, and he'd pay. Now before like he didn't know to take the basket, to get your groceries, so once that was kind of implemented like he's, he's really good at following instructions, so he will then get the basket and fill up all his groceries and pay for it. And then he'll walk from the Aldi out in XXX to XXX, that's where the slimming world group is.

R: Hmm.

P: So, he'll walk there and he's, oh like he's fully able to.

R: And so, there's someone with him for all of this?

P: Yeah.

R: And then he walks home?

P: No, so then he'll attend the group, and then he might need a little bit of support because his focus kind of goes.

R: Yep.

P: Ehm, so, he might think, if he hears a word, Ehm, there was one and he thought of an ad. And he said it out loud and he kinda burst out laughing. Ehm, so we just kind of have to bring it back to, you know, we're in a group and we have to listen to everyone else. Because, in that particular service user, he's very, self-focused.

R: Ok. Yeah

P: Like, it's his world

R: Yeah

P: Ehm, so sometimes it is good to kind of implement you know that everybody else, as you talk about your weight, you need to listen to everybody else's weight. You know, and then you'll learn new ideas and have different inputs.

R: Yeah, yeah.

P: So, that's kind of the supporting him for

R: Yeah. So, in terms of individual plans, these all emerge do they, from the lad's interests, or?

P: Yeah so, it depends like, ehm, there's been so much work going on in the day service, and, so we actually haven't been able to get the proper support plans say write ups and stuff like that

R: Yeah

P: Ehm, the paperwork of our side isn't very great like we wouldn't have ehm, much support plans and stuff, so what we would do is, kind of just document everything as to what they want to do and what they want to achieve

R: Yeah! Yeah exactly.

P: So, kind of goal setting and stuff like that

R: Yeah yeah!

P: Ehm, and his main goal was to ehm, one of them was to reduce his stress

R: Hmm

P: And the other was to lose weight.

R: Hmm

P: Ehm, because he was very stressed around that time, and he would have, he would have been very stressed around that time and ehm he was kind of having difficulties with, he calls them his habits. And it's kind of like jerking of the head movements

R: Yeah

P: And eye movements. But since he started slimming world, it was like it was a whole different person.

R: Yeah

P: Everything just really eased down, he wasn't getting those sort of movements and, and see then as well it was such a big change of the day centre splitting up, and still the work isn't done.

R: Yeah

P: So, they thought the work was gonna be

R: The building work?

P: Yeah the building work, sorry. That it was going to start in ehm, they said it was going to start in January, so, for about a year and a half they've been saying kind of the building work was going to be planned, but as you know, it takes a long time for that to process and stuff, so. Ehm, I think it was quite being upsetting that it hadn't started, and you know, so, but we're still waiting on the building work to commence, so.

R: And how did that affect him?

P: Ehm, quite badly that's when the,

R: Really? Was it the change?

P: Yeah

R: Yeah

P: It was the whole of New Directions just came, and that we're all going to be split into different Hubs, but yet our kitchen, kinda down in our area wasn't completed yet, and this was. So, we were all still in the kind of one building. Which we still are, we're in the one building so it's not actually completely split, because you know the lads can walk from

R: Yeah, yeah

P: Up and down, you know

R: So, that would have been upsetting him, and then he, you guys discovered slimming world?

P: Yeah, so that was the,

R: It's a really good example of how you've tuned into somebody and supported them.

Yep. So generally, for finding out about people, ehm, finding out about their hobbies and interests, or the kind of support they need, it's because you get to know them?

P: Yeah well get to know and observing. I think that's

R: Yeah

P: Observing as well is very, ehm, I think is important

R: Yeah

P: Because ehm, like another way with dealing with that service user's stress was, that ehm, it was a, he uses a tambura. And, it's an Indian instrument

R: It's like a drum is it?

P: It's,

R: What is it?

P: It's like a little box.

R: Ok

P: And it has kinda two little knobs there, and when he, the sound it makes it's kinda mmmm. But he will make it into a car noise.

R: Oh?

P: Like he's driving.

R: Oh

P: With the different tones,

R: Yeah yeah yeah

P: So, like if he's really stressed he'll be going really fast in the car

R: Are you serious

P: And, then he'll slower it down. And then he'll go, 'oh, I'm feeling better'.

R: Oh my goodness

P: Yeah. So,

R: So that's how you know?

P: Yeah

R: Well one of the ways

P: Yeah one of the ways yeah. And then I implemented as well, was a worry monster, because he

R: A worry monster?

P: Yeah they have, they're actually in the 2 euro shop!

R: Really?

P: Yeah. And ehm, what it was, it was quite visual

R: Yeah

P: And ehm very sensory as well like, he's very colourful and he's quite funny looking

R: Yeah

P: But eh, with that particular service user he would be very self-focused, on himself

R: Yeah

P: So, for him to worry about something, he wouldn't like to kinda say that he's worried, cause then, him saying he's worried, would be really focused in on himself and he'll worry about it more. So, with the monster, he sees that's the monsters worry.

R: Grand. And he puts it on the monster.

P: So, he writes down, he writes it on a piece of paper and the

R: The monsters worried

P: The worry monster eats it

R: Wow

P: So, it's kind of like a zip mouth.

R: Yeah

P: So, you'd put that in and then he'd close it up and he'd be very sympathetic towards him, 'awe it's ok', 'that's gone now'

R: Yes. Yes.

P: You know

R: Yes

P: So, it was really

R: So, who's idea was that?

P: Myself.

R: Super. It's a really good idea.

P: Yeah, cause I think it just takes from that self-involvement and looking at it as a different person as well

R: Yeah! Yeah!

P: And just you know so it's not

R: Yeah he gets it out, yeah!

P: Yeah. It really worked with himself anyway.

R: Yeah. Yeah yeah. Well they're two really good examples of how you tune in. And that is probably how you think your way through the day.

P: Yeah so like obviously if there was any sudden change as there's always change, in a day as much as we try not to change things, someone can call in sick, and so then when that happens, that's when you're preparing yourself as to what I can do to support.

R: Hmm.

P: So, then that's just again, ehm, with that particular service user, by keeping himself busy is what works really really well. So, if that kind of happens you're saying, ok we're guna go out straight away we're not guna sit around and kinda just wait or like if you have to do up the money. I'll just be like right, I'll leave that till I get back, my main priority then would be, to let's get the day going. Because then you're out of the centre and the focus isn't there then.

R: Yep.

P: Cause otherwise, what I have seen and observed before, is there would be a very lot of questioning, and then it's more hard for himself to come out of that stress

R: Yep. Yep. So, get up and go.

P: Yeah

R: Yeah. Hmm. Well they're really good examples of how you tune in. Ehm, so is there anything that could be done that would make it easier for you? Other than the building work or whatever? Is there anything that would make your doing the job that you want to do easier?

P: Ehm, I suppose staffing can be a bit tough.

R: Yeah.

P: You know, there's only three staff for six lads. It's very hard to get what you want, done. You know, especially ehm, person centred. Like that kind of one to one support, and especially for record keeping

R: Yea

P: You know it would be, like we would find it very difficult to kind of, you know, implement that through the day. Like, we haven't, as I said, haven't got the support plans

and stuff like that. It's kinda been you know, PCP's to be writing up everything like I know other, ehm, around the other areas, they would have PCP's. And then like I do be thinking, oh god like how could, I couldn't even find the time in the day to do that like.

R: Yeah

P: Cause some days like you wouldn't hardly sit down

R: Yeah

P: You know, cause our lads would be very, ehm, would really want your attention.

R: Yeah

P: A lot of them kinda would be very head strong to kind of want your attention so they're very very vocal, or you know, and I kinda noticed, if you are doing something and you're a little bit unfocused, then they would kind of grab you, you know, to kinda get your attention.

R: Yeah

P: So, like they do need their, you need to give your attention to all the lads.

R: Yeah

P: Which can be quite hard

R: Absolutely

P: to do.

R: Yeah

P: And then for yourself then as well.

R: Yeah

P: You know cause you're not getting that, five minutes

R: No space, yeah

P: to you know kind of relax and just get your

R: Yeah yeah

P: So, like you're coming home then and being absolutely exhausted then

R: You would yeah

P: You know

R: Hmm, hmm. So, staffing would be a suggestion?

P: Yeah. But, as probably resources and with money, cuts and financial

R: Yeah

P: It's probably not the, ehm

R: And what sort of time would the lads come in the morning then?

P: So, from about ten to nine.

R: Really?

P: Yeah

R: And then when do they go?

P: Ehm, for about, half three, four o'clock

R: Hmm, long day

P: Yeah

R: Intense?

P: Yeah. So, I kinda go in at half eight, every morning just so I can get the money prepared. So, I can kinda when the lads come in at nine then you can just give them your full attention, you're not kind of, ehm. Or if like I don't get to write in one of the books, I'll come in for half eight and you know, just kind of get the written work, of

R: Yeah

P: And that's how, I would go then about my day

R: And do you get a lunch hour?

P: Eh no (laughing)

R: (laughing) So, you're with the lads all day?

P: Yep. We would have our lunch with them.

R: Yes, but it's intense.

P: Yeah

R: You're not exactly chilling?

P: No. Yeah so it would be,

R: So how many hours a week would you do?

P: Awe you're asking me about numbers, I'm awful with numbers

R: No, like that's five days a week you're in from half eight

P: Yeah five days a week

R: Until what half four?

P: Eh, till four.

R: Yeah. And that's intense. No breaks.

P: No.

R: Ok.

P: Yeah, it's very tough because as well I'm doing my social care degree now at the minute, online. And I just

R: That's intense, awe it's really hard

P: Like I have an assignment due in two weeks and I'm literally like,

R: Where do you get the mind for that?

P: I know

R: Your head would be wrecked yeah

P: Yea I'm finding it very difficult

R: Yeah. Yeah, it's really hard.

P: Yeah.

R: Well, that's all we wanted to know really was how you think about and how you support the lads and how you get through the day. So, we got that and we got good examples, of how you do it, which is really nice its very person centred.

P: Is that enough?

R: No no no it's the real person-centred piece and how you fit that in. But, it's a very intense day.

P: Yeah. It is.

R: Yeah

P: Especially because one of our lads, we would consider very one to one.

R: Yeah

P: He kind of isolates himself from the group. you know like it's good to do those group activities where the lads are all kind of interested in what to do. Ehm, but like that we have one service user who wouldn't, wants to be different, wants to be, not in a group.

R: Hmm

P: You know

R: Hmm

P: And then I kinda, look at his home life and stuff like that. I don't think he has a lot of control, at home, so when he attends the day service he wants control, he wants to be independent. So, we try promote that as much as we can.

R: Yeah

P: You know

R: Hmm, well listen. That's been great.

P: Great

R: Yeah thanks very much

P: No problem at all.

R: Yeah no that's great.

Transcript Seven

R: So, really. The first question would really be about how long are you with [this service], and <OK> what sort of experience you have with adults with autism?

P: Ok, so I'm here since 2011, so six years.

R: Oh, yeah.

P: I started in the day centre in XXX, then over in the outreach, the outreach?

R: Yeah.

P: And then I started to work here in the [outreach day service] three years ago.

R: Hmm. So, you have a lot of experience.

P: Yeah.

R: Yeah.

P: So, basically, I have six years of experience with adults with autism, because before that I had no experience.

R: Yeah. So, you have a lot of experience now. So, really what we're interested in, is how you support people.

P: Yeah.

R: What's in your head. When you come to work, what's in your head about how you're going to support, say your clients?

P: Yeah.

R: So, first off, would you be doing a lot of one to one? Or, would you be with small groups, or?

P: Yeah, it's a mix. In the [outreach day services] we are lucky, you know. We have option to do both. So, we can work one to one but sometimes we work with smaller group. But, maximum three people.

R: Oh, yeah yeah.

P: So, it wouldn't be with a big group.

R: Yeah. And, would you be helping them in terms of their personal care, or?

P: Depends. So, it depends on the service user. Ehm, so, hygiene yeah would be something we support the guys with. But like, it's not necessarily physically supporting. It's just you know support them in a way, to suggest and you know to explain and teach them how hygiene would be important. We have one service user, a girl, who needs physical support, but you know, ehm, yeah. Other than her, everyone else is.

R: It's reminding people.

P: Yeah.

R: And, in terms of people's communication skills, how would you be figuring out the support that they need?

P: So, again it takes a while. It depends, so like if we have a new service user, or everyone basically. So, my approach would be to get to know the person first, spend time with the person, have like you know, have ideas what could work. But, like here it's a bit different like each house is a bit different, so like this house would be more, you know, eh.

Actually, it's a mix if I think about it. So, like everyone is so different here. So, eh, but yeah most of the guys would be verbal so they would, would be ok to understand, you know, speech. Eh, maybe some of them need, maybe you need to be slower, you need to speak maybe a bit slower. Or, you need to make more simple sentences, eh. Or, with some guys in the other houses we would use visuals. But anyway, it's up to the person and it's really individualised, I guess.

R: Hmm. And, then would much of your work be here, to do with people's routines?

Getting routines and interests and hobbies. Is that an important part here?

P: Eh, with some guys yes, with some guys. You know, with some service users yes, some service users no. so, it's so hard to answer this question. In general, yeah, some of the service user's routine would be important for them. And then we try and support them with their routine or even changing the routine, you know. But eh, most of them would be quite flexible, actually. And I think it's really interesting, there is a service user in XXX, and we like in the past we thought that he would be really you know, eh he needs routine, he needs his schedule and stuff like that. But, since he comes over here, at least once or twice a week, we realise that actually he's not that stuck with his routine, he can be totally flexible.

R: Yeah.

P: And eh, we can try so many more things here with him than in the other house where we were, you know, really stuck. It's a new environment for him, new people around and he's more, flexible. So, everything is...

R: Yeah. So, the difference then in this particular house, what would be your, when you come in in the morning, what would be your thinking in your head as you start coming to work? What are you thinking about?

P: OK, so like usually, who is in today, like because it can be you know, there are some movements between houses, but which service user is going to be in. What's their plan for the day. Do they have any plans? Because some of them would go to a course, or they would have something going on. So, what's their plan. Or if they don't have a plan, what kind of options can we, you know <yeah>, offer. Or, what could they do. Or, what

could we work on. So, that's in my mind first, and then they come in and it can totally change.

R: Right?

P: You know, like if eh, you know it's up to them basically. But, usually yeah like I just try to think, what's going to happen on that day and if something needs to be prepared, I can prepare it for them before they come in

R: Like what sort of something? Yeah.

P: Ehm, I don't know. For example, if I do, let's say key working with one of the guys, I would prepare I dunno like sheets for him. Or, if I know that, that his goal is to work on I dunno like money management, or relationships. I would try to think of exercises or ideas where we can actually practice or.

R: Yeah. And, where do all those goals come from?

P: Ehm, I think it's a mixture. It comes from them and from us as well. So, like eh for example, eh the guy I am key working, or yeah, he would love to go to London. That is his goal, that's you know, he wants to travel. He loves travelling. But eh, he's generating goals for me as well, for him you know. I don't know, so you know to go to London it involves so many other things. Like, you know, financial, planning it financially. So, it involves money management. So, or, or, ehm, yeah like applying for a passport.

R: Right.

P: So, he might not necessarily know that you know, these thing, he needs to do these things. It's me who <has to figure out the bits> explains the things, you know like 'ok that's great you have this big goal, but then we need to do this and this and this so that you can achieve that'. So, it's kind of a mixture.

R: Yeah.

P: So, it's his goal but I'm also adding things to it for him.

R: Yeah, the steps.

P: So that he can achieve that.

R: Do you have to keep that in a structure, or record it, or?

P: Yeah yeah yeah. So, like I planned it for him, like the steps that like, you know ehm the passport, and then the step by step there was a plan that first you go to the post office for the form. And then he did that. So, but I did write down the steps and I explained, and I just give him the sheet and you know like today you need to do this. And then he did everything independently, he just needed to know how to do it.

R: How to go about it. Yeah.

P: So, as I said it's kind of, this example is a mix.

R: Yeah. But would that be an example of a typical person who comes here that they'd be as capable as that?

P: See that's the thing, with him you need to help him with the steps that help him achieve something.

R: But he sounds very capable in comparison to the other people in the other parts of the service?

P: Yes. He is very capable.

R: Yeah.

P: So, he can do anything, anything he wants but he needs that extra bit of support.

R: Just for the steps.

P: Just for the steps, yeah.

R: Yeah. So, from a communication point of view, no difficulties?

P: See, he's the type who does have difficulties. Like if, but with the spoken, so with speech, not with speech but like if I talk to him, he might not understand. He needs time to process, so that's why I wrote down the steps for him, because if he reads it then he can read it again and again. He understands, it's just he needs more time.

R: Yeah.

P: So, if I just tell him that OK XXX, you need to go and do this and this and that. He might ask me two minutes later that 'Ok so what do I need to do?'.

R: Yeah.

P: With him, lots of repetition, if I do talk to him it's always repeated, 'So, X, you need to leave, what time do you need to leave your house, to get whatever?'. And then I ask him again and again, and he gets it, but it's more repetitive. And I found writing down things for him helps, so I don't have to keep repeating myself over and over.

R: Yeah. Exactly, and he doesn't have to be lost, yeah.

P: Yeah exactly.

R: Yeah that's super.

P: So, that's one example. But I think most of the guys here are quite capable to do things if they have the proper support.

R: They do sound it yeah.

P: Like, personalised support.

R: Yeah. Yeah.

P: They are unique.

R: Would you have to be tuned in to people's sensory needs? Or, are people fairly able to let you know?

P: Eh, again mix. Some people do, like X downstairs, she would tell you that 'oh squeeze', or you know she will need something, but some people don't.

R: Yeah

P: Or, are not able to. So, but you can, you know if you work with them you can understand or you can you know try different things and eventually find the right.

R: And would you find out much from your colleagues about what works for somebody and?

P: Yeah. I think we are really good, eh like you know our team is quite good. So, like on the team meetings we would share and help each other, so and there are many ideas that, you know, we try, and so whether it works or not.

R: Yeah.

P: But yeah, we do communicate. I think it's really important eh.

R: Yeah. Yeah. And you help each other out.

P: Yeah.

R: Ehm, so that's how you know because you get to know the person and the people seem to be capable, and then the team help each other out.

P: Yeah.

R: Yeah. So, you then would give feedback about the people you are with, working with, to the rest of the team as well?

P: Yeah. So, we have team meetings every month.

R: Every month.

P: Once a month.

R: Yeah.

P: And we would go through each service user and eh you know if someone gets stuck, let's say a key worker gets stuck or anyone gets stuck.

R: Yeah.

P: Ehm, we discuss and we come up with plans or ideas,

R: Right.

P: And then we try them. If they work, that's great. If not, then again like we try something else.

R: You try. So, you have that support?

P: Yeah. And I think it works here quite well. It's a small enough team and yeah, we are good at communication.

R: Yeah. Then, your responsibilities, so what, fundamentally would your responsibility be, when you come to work? What's the bit you seem to have to do?

P: Support the guys.

R: So, that would be the main job?

P: I would be, I would say that's the main job, to support them, and you know, to keep them, well to support them in a way that's not too much support? I don't know how to explain it.

R: Yeah, I do.

P: So, like eh, yeah to be there for them if they need, me. But try to give them enough freedom to you know, that they can try themselves. And, eh, like to, I just love to think that you know like what we are doing, in the future it's going to benefit them. You know to have a kind of purpose or goal that can help them. Because we are not going to be there forever for them.

R: So, some of them will be having less support?

P: Yeah, I think.

R: They'll be more independent?

P: Yeah. I think that would be the goal here.

R: Yeah.

P: That's what I would love to think. You know, that they are here, they come here, they, we give them tools and we give them you know, like skills, maybe to, eh, to use and apply, I guess. And, but yeah, it's hard it's so slow, though.

R: Yeah.

P: So, that's what's difficult because you know, they need time. So, my goal would be that yeah like you know, help them in their future but at the same time yeah, it's really, really slow.

R: So, that's your main purpose. And then other kind of tasks and things. Do you have much to do with health and safety, or procedures?

P: Oh yeah, yeah like the format yeah. Health and safety, yeah. Health and safety, yeah.

R: When do you fit that in?

P: Ehm, I guess we are supposed to fit that in every day?

R: Really?

P: I guess so. Like, you know, like health and safety, like you know they do the cooking. So, you have to be careful how they cook, you know the cleaning. Ehm, yeah whereas some of the guys might have medical issues, or they have medical issues ehm, though we don't register any medication or you know. We don't give them any medication. But, yeah like I guess we need to,

R: So, they give themselves their own medication?

P: At home.

R: At home?

P: Yeah.

R: Yeah.

P: But you always need to be aware of these things.

R: Yeah. Exactly.

P: Ehm yeah. And procedures? Like, what type of procedures?

R: Just, if you. Have you worked in the residences?

P: Eh, no.

R: So, it's a different kind of, they have to get through a certain amount of things, getting people up, dressed, fed, <OK> you know, keep their requirements about how they manage their cleaning products.

P: Ok.

R: Do you have all of that?

P: We do have the cleaning yeah. Like the, but it's, yeah like where we store our things, but I guess here it's not as, ehm, it's a bit different yeah compared to the residential.

R: So, that kind of work doesn't take long?

P: It doesn't take that long.

R: Your work is really about.

P: End of the day, like half an hour, one hour of the day, maximum.

R: Clean up. Tidy up.

P: Yeah.

R: Yeah. So, it's really quite different.

P: Yeah.

R: Yeah, yeah. So, you have an independent group of people, they come, they go, they have goals.

P: Yeah.

R: Ehm so, is there anything you think that would make it easier, or better for you guys to do your job?

P: Hmm. Do our job. Maybe, eh yeah, it's not up to us, but maybe resources. I don't think we have enough resources. I think general, it's a general problem. So, like our goal is to try to you know, integration and you know, be in the community. But, it's so hard because the community is not always open for the guys to do things or to try things. And we don't always have the, have enough resources I guess. So, for example, many of our

guys would like to work. But it's, yeah, it's not impossible, but it's not really easy either.
So.

R: Do you, do you have a role to support people in getting jobs?

P: Yeah like, in a way like if that's their goal.

R: Goal. Yeah.

P: Then yeah, we try, you know to support them in how you go for an interview, you know what do you say. First of all, what kind of job do you want to do?

R: Yeah.

P: But I find that it's a bit difficult. But again, it's, maybe just people need a bit more education about what autism is. Because it seems like they get scared, or they have this stereotype in their mind and they just straight away say no, 'oh we don't need anyone now'. For example, with X, we did the job shadowing day, I don't know whether?

R: Yeah.

P: Yeah. So, we did that. And he was in a pub.

R: Yeah.

P: And he was amazing like he recognise, like he can remember everyone's name, like straight away.

R: Wow.

P: Like he was eh, you know, pouring the, he did the taps and stuff like that. He loved it! And, ehm yeah so, we tried to get like maybe an hour or two hours per week, for him. Like maybe first just to volunteer, whatever, so not, paid, you know. But, no. so, it's kind of hard.

R: Hard.

P: Maybe you need to find, you need to go, yeah there's the thing so maybe you need to go into more places and try more and more places. It's just yeah, it's tough.

R: Yeah.

P: But, I find, maybe volunteering is a bit easier?

R: Yeah.

P: But it's not that easy either.

R: No, yeah. So, other than resources, is there anything else?

P: Hmm. That could make our life easier here?

R: Yeah.

P: Ehm, not sure. I find with our guys, what's difficult sometimes, is OK they are adults, but they live at home. Which, is not a problem. But they do live at home.

R: Yeah.

P: So, the influence of the family is quite a big thing. And ehm yeah, it's not something that can be changed, or I don't know. I don't really know what could be done. But I find, that that part is quite challenging, sometimes.

R: Yeah.

P: That we are, you know we do something here, and then they go home, and they don't really do anything at home. Because everything is done for them.

R: Yeah.

P: So, we are trying to achieve their independence, but at home it's totally opposite.

R: Yeah. And would you have much work with them at home?

P: Eh, we don't do that, but actually I think we are going to start doing that. I know with my, so with the new guy I am key working with, I would like to do that with him. This once we go home to his house, or meet at his house and work from there.

R: Yeah.

P: Because it's lovely that he can cook here. But he has no idea how to do it at home.

R: Yeah. Yeah.

P: So, I think I find that it's something that needs to be changed.

R: Yeah.

P: And then also with the parents to also make them, less anxious I guess.

R: Yeah. Yeah. Understandable, yeah. They see them as children.

P: Yes. So, that's what I find a challenge. So, if that could be changed and there was a bit more co-operation, or I don't know. And then the flow of information from both sides,

R: That they know people are doing things, yeah.

P: Yeah. So, it's you know, from our side or from their side would be great. But, at the same time, from our side, it's a dilemma that you know they are adults we are working with adults. So, how much more information are you giving to a parent who is actually there, and.

R: Yeah, it's for the lads to do, yeah.

P: So, here I find that one is a challenge, sometimes.

R: Yeah, I can see.

P: Support. Or, the parents have an idea, strong idea, or opinion that needs to be done and what we need to do.

R: Right.

P: That can be also a challenge.

R: Yeah. Yeah.

P: So, yeah. I think that would make life a bit easier if there was a, I don't know exactly what you need, communication, or something.

R: Some kind of discussion, yeah about what are people's abilities.

P: Yeah.

R: Yeah. Well, that's it. Thanks very much, that's all the, yeah.

P: Yeah? Alright.

Transcript Eight

Pilot interview 1

R: Hello and thank you for coming

P: Thanks

R: So, what we're going to do just for confidentiality is code this with a number so your number is 01. You've signed the consent form and you've seen the PIL. So we'll start with the questions and the questions were sent out to you already?

P: They were.

R: Yea. So, straight off, how many years have you been working with adults with autism?

P: A year and a half.

R: And how long have you been working in this setting?

P: A year and a half as well.

R: On average how many service users do you support at any one time or during one shift?

P: So during one shift it would be two individual sessions or if there was a group, probably one individual session and a group could be anywhere from 2 to 6 or 7 people. Depending on the day.

R: And tell me a little bit more then about how you support a service user doing their hobbies or interests? Would there be someone that you could talk about?

P: Yeah, so I suppose different ways would be either through individual sessions or groups, so... I guess through individual sessions it's with one person so you would explore their interests with them first, and see what actually they are interested in doing. Em, and then there might be the opportunity I suppose to get to do that together through individual sessions, so whether it's they want to go walking or baking, I suppose... One guy I'm working with at the moment wanted to try out baking, Ehm... so that's something he's doing at the moment within his individual sessions within his house, and trying to get used to using the kitchen, following the steps and everything else.

R: So how did you explore? So do you just kinda come in and say hello and then what happens?

P: Yea well I suppose in terms of exploring their interests and what they would like to do?

R: Yea

P: Yea, well I suppose we're lucky in our service that we know them quite well, so we might have this exploring every couple of weeks or months. It's not so much a first interaction.

R: Yea

P: But I guess whenever they don't really have anything to do in their individual sessions or they're kind of unsure of what they want to work on, you might have one of those conversations of, you know, is there anything you're interested in doing. what I've kind of found recently is using something like an interest checklist is helpful because sometimes you ask them and it's a bit of a hard question to say is there anything you're interested in or do you have any goals, and I've found one particular person you could ask him that and he'll just say 'Oh I don't know there's nothing really I can think of. And then if you did the interest checklist there was 10 to 15 things that actually he really wanted to try and get involved in. So sometimes it's that imagination or not being able to think of something but by having something like that makes a big difference. And I suppose suggesting things to them as well like d'you know there's people who are really interested in music but, sometimes you might have to suggest what about getting involved in volunteering or what about this? I suppose from getting to know them you can kind of come up with your own suggestions as well because sometimes they might not think of it off the top of their heads.

R: So, would one session lead onto the next then? Say you were doing something and there was a hobby or interest, would you then kind of plan and progress that or would it be a once off?

P: Yea well you'd hope to plan and progress it, especially something like baking. Like I was actually baking with someone today just before I came here and I suppose it's different in our service because the next session might actually not be with me it'll be with a different staff member, so that can make it a bit harder to do that progression piece because you have to pass that onto them, what they're working on and it's not as natural sometimes. But say today like he has baked this same recipe now 3 or 4 times. So I would have said to him like how do you feel out of ten, how good do you think you are at doing this, like how well are you able to do it on your own? And he said 7 and he'd like to do it once or twice more.

R: Right, great.

P: And then move onto the next recipe, so I suppose in that way he wanted to cook the same recipe a number of times and then when he feels he can actually do it on his own, then move on, rather than try a different thing with a different staff member each time.

So I suppose the recipe is what stays the same even if the staff members changing and just trying to stick to following the instructions and prompting to look at the instructions. And trying to I suppose approach it in the same way but you don't know with different staff do some people help a bit more or do some people leave it more up to them, that's where the challenge can be sometimes like that, with the following on session after session.

R: Yea. So people then have an opportunity to explore ideas and then to practice and do more.

P: Yea. And I guess it's different if it's something that they can't necessarily do within a session it might just be all exploring – is there something in your community that you can do that or will we look up things online. So you might not actually get involved with the person but you there's a guy at the moment looking into getting into a community garden, so I suppose a couple of sessions around researching them and then contacting the person and then role playing the phone call with the person..

R: Really.

P: Now there's a meeting, he's arranged to go next week to the community garden, he wants staff to go with him for the first time, so then that might progress I suppose to going on his own. I suppose in the community then is another way to get those interest. so it's better I think.

R: So that's quite a long-term thing, it isn't just day to day were doing such a such, it's a real long-term plan around their hobbies.

P: Yea. Well that's what we try and do but I do think sometimes with the staff swapping each week it's not always like that. And from week to week someone might want to cook and then next week they might want to do something else... so it doesn't always happen that way, ehm, it depends on the person, but I do think having the staff swap and having them plan sessions. And sometimes they don't want to keep doing it so sometimes things can get dropped in that way, like you might bake once and then not again for a couple of months.

R: Yea. So, then moving on to people's daily routines, would you be supporting people in their daily routines?

P: Yea well I suppose were not obviously living with the people or it's not a residential service, but I suppose things have changed a good bit recently, in terms of we used to kind of give out people's hours or their sessions and just show up to their house at that time. That was kind of how the service was set up.

R: Oh?

P: Em, and recently with one guy in particular, he had a lot of sessions and this was happening and we just felt like he didn't really have a concept of time or routine. It wasn't really within his control, people just showed up and then you did whatever and then they'd leave again. Em so I'd be his key worker at the moment and were really trying to get away from that and that he has to... we ask him to plan the sessions in advance and now we don't really go to his house unless there's a reason. So today I went because it was baking, ehm, or if he wants to do household skills or something. Otherwise we say well meet out in the community, because then I suppose he has to, first of all plan it in advance. Second of all, figure out what time he actually has to get up, have his breakfast, do his other things. Because he really struggles with that kind of time management piece and planning and organisation. So I suppose trying to support him in that because we really felt like by me showing up to his house at a certain time that doesn't give him any of those skills to actually have a routine then later if he wants to do other things, he ends up late or he doesn't know the bus to get. That kind of thing, so I suppose trying to support each step of that. Some of that you actually need to have a session before the session: OK what time are you going to leave your house and what time are you going to have breakfast and what bus are you going to get then and where are you going to meet them? So I suppose that's kind of the change now in routine and having more control over time.

R: So the person is really learning to structure their own routine?

P: Yeah. Rather than it being more passive which I think it was for a long time.

R: Yeah. So that's interesting that it is that person's routine. Yeah. That's a lot of work.

P: Yeah it's more work than just showing up and you end up having to cancel sessions because they're late, but we used to wait for them for a long time.

R: Yeah it's very active.

P: Yeah I think trying to get them better at structuring their own routines and for things like if they have an appointment in town or someone else to meet you can have a bit more confidence that they might be able to do that rather than us kind of...

R: Yeah. And then ehm, this question is about supporting people in communicating their own needs. Would you have to do that now or are the people you're with kind of.

P: Yeah well I suppose everyone we work with is verbal so they can tell you what they want to do. But there are different ways still to support it. Like some people we support would actually communicate better by text or email rather than asking things in person. You know when they have a bit of time to think about it and then reply to your text. We notice that sometimes with people like you might ask someone something in person and discuss something but they wouldn't have much to say. But I suppose we have the ehm ...

a work phone so we're lucky that we can send someone a text if you're planning a session for the next week or few days' time.

R: Right

P: And talk about something with them, or suggest an idea over text. Em and definitely I think even though they are verbal, you can over, I think, expect them to know, to hear everything you're saying and to process it. But still a lot of the people we work with do have trouble processing information, so definitely for meetings and things like that when you're talking about a lot of stuff at once, I'd always have things written down as well and have an opportunity for them to write onto that document...

R: Really

P: So that you know they have that time and I think that makes a big difference. One for keeping the meeting a bit on track and getting everything said, but I think for a lot of people having it written down makes a big difference.

R: So again, it looks like there's planning.

P: Yea

R: You don't just rock up and have a chat.

P: Yea well I suppose that would be more for a... say one guy wanted to talk about money management and for his parents to be there. So that was more of a structured meeting, and I think there had to be something on paper there to say what we wanted to say and to give him the opportunity to say what he wanted to say. Em, but I suppose for a session it would be more casual you just would probably show up and have the chat, but we have these key working meetings that we would use as well. So they're meant to be once a month, but we've ended up doing them a bit less than once a month because we feel that that's too often to say what are your goals this month. Eh but that's literally a piece of paper that says you know what's your feedback on the last month, how things have been going, what do you want to focus on next month... just a blank enough page but I suppose that's the structure around it as well so it's a bit more structured.

R: Yeah. And where does that go then, that information, where would that go?

P: That would go into their folder.

R: Yeah. And who would read it.

P: Em I suppose the point is that staff would all read that so they would be up to date. But I guess we would also send out emails if there was something new that came up. And then those kind of key working meetings would go into their, every three months they would have a key working report done up. So that would summarise everything they'd been working on and goals for the next few months.

R: Yeah

P: So those more informal ones get put together.

R: Yeah. Ehm, this other question is about supporting the persons in their social contact through different activities.

P: Yeah well I suppose on our team a lot of that would probably happen through group work.

R: Right.

P: Because I think a lot of the service users we work with one of their biggest barriers sometimes to doing things is that they don't have someone to do it with, or they don't have a lot of friends outside the service. So definitely group work has been a really big positive thing on our team for social contact. I think everyone's different like I'm thinking of a group we did recently it was kind of a creative group. Em and trying to have it more service user led, so they had different projects they wanted to work on and planned for a number of weeks. But there was some people who came to that who came and chatted and no bother you didn't really have to do much prompting or, you know you didn't really have that much of a role within social contact other than having the group there. But there's one guy who would be more introverted, he'd kind of be in the other room it's easy to nearly even forget he's there because he'll be in the other room, does a lot of self-talk, and doesn't particularly want to engage that much. But I think you know to remember to try and include him in some way, give him something to do so say we were making a stunt dummy for the guy's film that he wanted to do. And you know just asking him to come in were cutting bits of rope would you mind cutting a couple of bits of rope to this length and then he comes in and he says 'oh I think that stunt dummy is cool what are you making?' and has a couple of sentences back and forth and then he goes back into the room. So I think it really depends on the person but sometimes the group work just naturally gives the social contact but then for other people having that activity to focus on and bringing them in and giving them a specific role and asking them to do something and have a bit more of a role as a staff member, makes a big difference, and then over the weeks they might get more and more involved or then they start chatting to the other people in the group.

R: Yeah. And then the groups are planned they regularly happen?

P: Yeah well now they're kind of more project focused, so there's a few people have a shared goal. We had a housing list group there which was kind of boring in a way because the goal was just to get on the housing list. So they came and we told them about the

housing list and getting on the housing list and getting documents together and then when that's done then the group is over.

R: Yeah. It's all task focused...

P: Yeah it's good I suppose because we would have had one of those in town where the whole group was to go to the revenue office and get a form stamped. But then I suppose encouraging... like that only took about 20 minutes. But then to say OK were going to leave now but you feel free to go for lunch together or you know, you stay in town. So I think that does naturally sometimes they might not be as likely to invite each other for lunch but sometimes you have a group that just ends up somewhere and then staff leave. I think that did get a lot of people more comfortable spending time together away from staff. and then they have started to just meet up outside of us as well, which is just great.

R: Yeah. And then the last question is about supporting people during meal times. Would that be something that you do.

P: Not a whole lot, because we don't serve meals or we don't work there but I suppose the only times we would would be when we would be doing a cooking group. because then that's the only time I suppose that there would be food served in work or that people would be eating there. Em, I suppose through that everyone would kind of have a role whether it was cleaning up or cooking or a certain part of the meal. Everyone would sit together at the table, staff and service users, and I suppose it would be quite sociable and relaxed.

R: Really would they?

P: yeah.

R: So that's interesting. Everybody sits down.

P: Yeah. I mean everyone would sit down at the end. I mean what would usually happen is, during those cooking groups, the service users would eat what the cooked and staff would just have their lunch at that time. Em, so it would be kind of a social thing then at the end.

R: Very social.

P: A lot of the guys would call that group the eating group not the cooking group. They just came for the meal more so than the learning how to cook. But they did learn to cook a bit.

R: That's the... it's the seeing the meal time as social is actually the, why we have that question, is to look at the socialness of eating. Because often when people are in services they don't eat socially. There may be provided with food but, yeah. That's so, the part of

the service you're in, your experience would be different if you were in a different part of the service.

P: yeah definitely.

R: Yeah. So this is capturing this. That's really useful. Thank you, very much.

P: No problem.

Pilot Interview 2

R: So, thank you again, this is person one, interview 2. And you've signed the consent form and you had the information given to you previously.

P: Yeah

R: So, we're going to talk a bit about, the first interview you were telling us about someone who you were working with as a key worker

P: Hmm

R: So, if we keep talking about that person, you might just then explain how you do your support, so really, why do you support them in the way you do? You were talking about the household routine and the baking. Why would you do it in that way?

P: Ehm, well I suppose the things about routine, would be about giving more responsibility to him to organise and plan things

R: Yeah

P: And the real reason behind that is so that he can actually learn to do that for himself and I suppose, not feeling like the service is doing him a dis-service by showing up, and for him to expect that when you're meeting someone they just show up. Eh, no when you're meeting someone you kind of have to agree a time, and you kind of have to have contact with them and you have to be there on time, or else it doesn't really work.

R: Yeah, right

P: Ehm, thinking for his own life, his goals are he wants to get a job and he wants to move away

R: Oh right

P: Ehm, and really that's not going to happen if he doesn't have the ability to be somewhere on time

R: Yeah, yeah

P: and get a bus and he's well able to get a bus, it's more that he's an hour late. [laughing].

R: Oh, yeah.

P: It's more the planning and that side of things and that's why, I suppose, trying to have that happen within the service so that that can be followed on then.

R: So, basically, what you are doing is, related to his own goals, and you've kind of identified, you've all, himself and yourself, the planning and the timing is crucial.

P: Yeah, exactly, and I think he would have had, like he had an interview for, with a job officer, and the whole thing you know like, he was late, he was really inappropriate, and

all this kind of thing happened. And while, his goals before that, weren't exactly, 'being professional' and 'being on time'

R: Yeah

P: From that it came, well actually, that's going to be your main barrier to employment if you can't get past that interview stage you can't get there

R: Yeah

P: Ehm, then actually that's what we really need to work on, and can we do that through everything, even if we're just meeting up for a walk, still it's, it's not in your house, it's we're meeting at the place that we're meeting, and if you're not there in ten or fifteen minutes I'm going to leave. Because that's what would happen in an interview, or any kind of appointment.

R: So, all questions that we have here, are really based on that interpretation, his needs, where he's going with his goals,

P: Yeah

R: So things like ehm, when you support him, in the way you do, what's running in your head, what are you thinking about?

P: Yeah, I suppose trying to think about, trying to think if you weren't there

R: Oh Ok, yes!

P: Well like for the baking which is the other thing I've been doing with him recently, obviously trying to get him to do as much for himself. Sometimes he will need a prompt from me to read something, or to do something. But trying to get him used to doing as much for himself, because the last time I did it with him, he did everything perfectly, but then said he was going to the bathroom. And then like things were going to be ready in two minutes to take out of the oven

R: Huh, really?

P: And, I would have said, you know, 'fine, go to the bathroom but you need to be back really quick because they need to be taken out they're going to burn'. But he was gone to the bathroom for about 15 minutes, things were totally over-cooked, like I ended up having to take them out of the oven because whatever, I didn't want there to be a fire!

R: Yeah

P: [laughing] And like, then he comes back and I was saying like look, you know, that wouldn't have worked if I hadn't have been here

R: Yeah

P: And he says, 'well, thank god you were here'. [laughing]. And I'm trying to get them to, you know, to be, because sometimes you're, I'm thinking that,

R: Yeah

P: Like, how much can they do for themselves, but it can be hard to get them to think that way as well, when you are there. So, trying to take a step back when you are there as much as possible,

R: So

P: And remind them each time, you know like, he did know I was there, so really he probably didn't care that much that he was in the bathroom, or whatever, but if he hadn't been there things would have burned and there could have been a fire. Trying to remind him of that all the time, and when we are cooking, you know, instead of asking me a question, look at the box, what does the box say, what's the first step.

R: Hmm

P: Did you forget something? Well look at the box. The first step was to turn on the oven, you didn't do that.

R: Yeah

P: But, you know look at the box instead of looking at me.

R: Yeah

P: Because, that's going to be there when you do it next time

R: So

P: Ehm

R: Yeah that's really helpful because you are actually clearly going in there, knowing where his goals are, but you're really knowing his needs are, the timing, the responsibilities, and the planning

P: Yeah

R: So, everything you do is, you trying to see yourself out of the picture

P: Yeah yeah. And obviously relating that back to his interest's as well. Like before, if you pulled him up on saying something inappropriate or being late, he didn't really care. But to bring it back to well, in a job this wouldn't happen, or

R: Perfect

P: If you were in work, this wouldn't, be pulled up

R: OK so it's reality checking

P: Yeah

R: Yeah yeah. Ehm, so how do you prepare yourself now, when you're going in to him? Do you have to put switch on and say, I must think like this? Because it would be different with everybody, I presume?

P: Yeah. Different with everybody. But I think with him it's thinking like that as well, because it can be easier I think, you know if someone says something, I'm trying to think all the time of that, what are his goals, his goal is to work, his goal is to be as independent as possible, and you know sometimes if he says something really inappropriate, he'll be constantly saying inappropriate things. And it really annoys him when you pull him up on it. But when you discuss that with him, and ask him, well what do you want me to do? Do you want me to tell you when you say something that's offensive to me? And he says yes. And when you do it, it really annoys him, but I think to keep reminding yourself that it is hard to keep doing that, for me.

R: Yeah

P: And actually it doesn't really offend me that much when you swear, but we agreed that you were going to treat this as a professional environment, so I'm going to have to act that way. You know, because with some people, they'll say like I'm just someone who swears, and I don't care and that's just my personality. So I wouldn't really have a huge problem with that, because that's them and they're not hoping to bring that anywhere, maybe. But if he actually wants to be able to go in and get on with people in work

R: To work

P: Then, that is something you have to be aware of, and pull them up on I suppose, so trying to think of, where they want to be, I suppose.

R: And that's how you prepare yourself.

P: Yeah

R: And where that person wants to be, and then every action seems to be coming from that.

P: Yeah

R: So, ehm, do you do the planning for your use of the materials and equipment? So, you were just saying, so with the man with the box, you keep taking yourself out of the picture?

P: Yeah

R: Yeah. So, you actually have to be thinking about that

P: Yeah, I suppose there wouldn't be a huge amount of planning around equipment. He would get all the ingredients and he'd get everything

R: Yeah

P: But yeah trying to get, I suppose yeah that is it, trying to remind him to buy the ingredients but, that he's doing, he's getting everything.

R: Yeah and for yourself in that situation, what are you telling yourself?

P: About,

R: The use of the materials, and the equipment?

P: Yeah, I suppose the same thing really that, these

R: The stepping back

P: Yeah, this, you're not going to show him where something is, or pass him something, and sometimes it's harder

R: Yeah that's why I'm asking

P: Like, the same thing, if they're reaching for something, or they're about to do something wrong, it's almost easier to hand him the right thing, or to say, look this is where it is.

R: Yeah

P: Or, even to start busying yourself and start putting things away while they're cooking because it's harder to stand there and just look at them [laughing]. But yeah, to remind yourself not to do that, and actually even though that seems simple, just to put the butter back in the fridge, or whatever, you're just helping out, actually it's better to leave that for them to do, after you're gone.

R: Yeah

P: Yeah

R: So, that's the same thinking right through.

P: Yeah

R: These are questions that mightn't be relevant, but, would you be thinking about the physical, social and sensory environment for that particular person?

P: Yeah I suppose, not so much in terms of the cooking, cause I think he's in his home house and he's quite comfortable there

R: Yeah

P: Like he has that, like, it's fairly blank walls, I think from a sensory point of view he has it the way that it suits him

R: Ahh, yeah

P: But definitely when you're out and about you would think a lot about the sensory and social environment in terms of that certain sounds would really stress him out, and if you're in a place and there's kids chatting or talking, or laughing, or crying, he's going to get really really highly, highly stressed

R: Ok

P: And he's much more likely to do all these things he's trying not to do then, like do something really inappropriate or shout at someone,

R: Oh right

P: So I suppose you're not always going to be able to avoid those situations and usually you can't, but being conscious of it and being conscious then of, you're not talking to him then too much, if you're in a situation like that and leave him with his earphones in.

R: Hmm, hmm

P: So yeah, you'd definitely be conscious of it when you're out in the community I suppose more so than in his own home.

R: And, how did you get to know what works for him?

P: I think through trial and error a lot, ehm, trying things, and I think, lot of the changes that have happened with me working with him, have been from working a certain way, and it not working as well, or ehm, and trying to always bring his interests back in because I think, there was lot of these like, you know, he might not be particularly motivated for something

R: Yeah

P: But to really bring it back to his interests, like with the organisation and planning, ehm I was really trying to get him to use like a weekly schedule or something, because he had all his household tasks, which was brand new to him, he was kind of forgetting things, in terms of the washing and the cleaning and stuff. And then his sessions, he was really struggling to plan them in advance and it was all kind of being done on the day, or the day before, or nothing and then it's cancelled.

R: Hmm

P: So, trying to get him using a weekly schedule, and he just didn't want to, at all. Which is fine, he said he wanted to and we had a weekly thing up on his wall like a whiteboard, we had pens for him to draw on, different colours, and it just wasn't working. But then I think thinking back to what he's really interested in, and he's really into drawing books and comic book characters. So I kind of had the idea to ask him to draw a character of each goal he has or each cleaning activity

R: Right

P: So, then he had up there you know, the evil character, planning and organising his next [laughing] ehm, crime, and do you know, one of his other characters sweeping the floor, or whatever. And it did, like, he still doesn't use the thing all the time, but having ok put those, stick them up on the days that you might want to do that, and I think having it kind of visual,

R: Yeah

P: instead of ok could you slot in when you're going to do that. And having it that some things stay there the same, you know that laundry is the same every week. That's grand, that just stays stuck there.

R: Yeah

P: Ehm, and making it a visual thing, instead of asking him each week to write it up together

R: Yeah

P: So, I think that that comes from just thinking about things in a lot of different ways, because really, at the start, he said he would use a, a visual schedule, and it seemed like something that would work, but then it didn't for ages. And just trying to, I suppose, try a few different things, and there's still probably more we can do, in terms of planning

R: Hmm. But you figured his way of doing a visual schedule was, his way

P: Yeah and always bringing it back to his interests and things that he is, like there's a lot he's not motivated about, and planning is probably one of them, but the one thing he is motivated about is the drawing and his comics, so is there any way to combine, I suppose.

R: Hmm Hmm. And, you've told us like what you do if things don't go well, you've just given us an example, you just,

P: Hmm. You just keep trying a different way I suppose.

R: You try a different way, yeah, yeah. And look for a creative notion, yeah

P: Or I suppose sometimes eventually if things don't keep going well, you might just move on to something else

R: Yeah

P: You know

R: Yeah

P: But yeah definitely there's trying things different ways, and I suppose we're lucky that we see people over such a long period of time

R: Yes

P: that you can, you have the freedom

R: Yeah

P: And you have long amounts of time to explore things and discuss things with them and then sometimes you come full circle and come back around

R: Ah ha, yeah yeah yeah. Ehm, so do you feedback then to others about how you your engagement or what's working

P: Yeah, yeah, definitely,

R: Yeah you would feedback

P: I suppose that's why we kind of have the key worker system that everyone kind of works with everyone. So like he might have three or four different staff working with him at a time,

R: OK

P: But that the key worker is kind of responsible for putting it all together into these key working reports, and if there is something that comes up, emailing, so

R: Right

P: So, he's the guys as well who is getting involved in the community garden, so making sure, ok could you remind him about that, has he called your man, do we need to put it in the roster

R: Oh yeah

P: So, I suppose, when anything new comes up, I'd be the person to kind of communicate that, and then at meetings, you know I'd be the one to say, you know, this is what we're kind of working on this month

R: Yeah. So, your work with him, that's, that would be, you don't have to fit him in around anything else? So when you go with him, that's your proper job?

P: Yeah, yeah

R: Yeah, yeah, yeah.

P: So, you have a two-hour session

R: Yeah exactly. Yeah yeah. So that is your routine is you're with him for two hours.

P: Hmm.

R: Yeah. And, is there anything else that you, from your, your, the way you do your organising and your routine with him, is there anything else that might help, or anything else that would be?

P: Hmm, yeah I think what we're finding a lot now is that actually, he has too many, sessions, and that's partly why he can't, he can't make a plan for all of them. Because, he doesn't have four, five goals in a week, and a lot of the time he just likes to do his own thing.

R: Yeah

P: But we're a little bit stuck, in that he's entitled to this many hours and that's how many he has. So we've gotten away from that a bit in terms of the planning and if he doesn't have something he just cancels his session. So, he's actually, he's having less sessions now, but it's from him,

R: Yeah

P: But he still does prefer to meet staff sometimes than not meet staff

R: Yeah

P: But doesn't particularly want to do much?

R: Yeah

P: And then you feel like it's just company, which would be fine if it was just once or, every one or two weeks meeting up for a catch up, but if it's every day then that's not really showing him what it's like in the real world

R: Yeah

P: and he's kind of relying a lot on staff for that side of things, so I think that's probably one of the hardest things with him that if he was just coming to us and if we were just making these appointments around him based on what he wanted to work on, that would work better, than well actually you have these sessions regardless of whether you plan it or not.

R: Hmm.

P: It's a big barrier to the planning and organising.

R: Yeah

P: When there's not as much of an incentive for him to do that because actually, he can meet us, if he comes to the house, or whatever.

R: Yeah, Yeah. Well that was really helpful

P: Great

R: Thank you very much

P: No problem.