

Suzana Hercegovak

So welcome, everyone.

Golly gosh, we're in to 2019 and it's March.

Far out, I don't know how that happened, but the nice thing about that is that we're heading in to the whole new round of the Summer Foundation Breakfast Series, and this year we've got a real treat of scholarship presentations, I think most of them are, the majority, three out of four, Cathy? Yes, or maybe it's only two, maybe it's only two out of two, all right, half of the presentations are scholarships, and we're going to start the year off with a lovely presentation from Suzana who was an Allen Martin scholarship recipient and this is the work that she undertook with that scholarship. So Suzana and I'm going to have a go at her name, Hercegovak?

SH: Hercegovak.

Suzana Hercegovak is all the way from South Australia to come and present and as those of you who have looked at the Allen Martin scholarship conditions know that it's now an Australia wide scholarship, but part of that is that you must make a commitment to come and present, so that's really lovely to come to visit Victoria and hopefully have a bit of a holiday as well.

So Suzana undertook this work as part of her Honours graduate in OT while she was at the University of South Australia during her community and clinical placements and she was working with various client groups including people with intellectual disability, in sub-acute neuro-rehab setting and in community rehab, working with people with mental illness and all other people and very much looking at what are the experiences like for volunteering in terms of finding productive roles for people, but really looking very broadly at different people's perspectives, so we're going to be very excited to hear.

As always, we really invite discussion, but we'd like to hold most of that to the end because that just helps with our video recording, but if you do have a really important question, Suzana is really happy to take it, but we'll just need to make sure that we get the question captured as well.

So please join me in welcoming Suzana.

Thank you.

(Applause):

SH: Thank you.

Thank you so much, Margaret for that lovely introduction and thank you all for coming and joining us so early this morning.

So yes, once again, my name is Suzana Hercegovak, I have a Serbian background, so I don't know if any of you have a Slavic background that might be more familiar to you.

So today, I will be presenting on my primary study of my Honours thesis, which was focusing on the experiences of volunteering following acquired brain injury.

So I will assume that if you're here, you might know a thing or two about acquired brain injury already, but I have just included a bit of a refresher.

Acquired brain injury, and I will also refer to it as ABI throughout this presentation, is a health condition where damage has occurred to the brain after birth.

It has a range of different causes and some of these can be classed as more sudden onset, so some examples of sudden onset ABI can be anything where there's a sudden physical injury to the head. This can happen during sporting accidents, motor vehicle accidents, workplace accidents. Also, quite commonly, sudden onset ABI can result from stroke.

Some other causes of ABI can be more insidious onset, so this is anything that develops over a longer period of time.

This can include the prolonged use of drugs or alcohol, even illnesses that affect the central nervous system, so some of these can include Parkinson's disease, Alzheimer's, cancer, cancers that reside in the brain or even multiple sclerosis.

So given the range of different ways that ABI can occur, it is quite difficult at diagnosis to say how it might affect someone's life.

Quite often, there are some ongoing changes in physical and mental function and these can affect how somebody goes about their day-to-day life.

According to the Australian Bureau of Statistics, in 2007, there were at least 430,000 Australians who reported either activity restrictions or participation limitations.

People with ABI also reported accessing more support groups and they reported more health conditions than the average person with a disability.

So, I found this really interesting to note because it shows that ABI isn't a straightforward health condition and how it's going to affect someone, it has a really complex impact on someone's life. ABI has been known to impact areas such as self-care, productivity, leisure, social relationships.

Some of the research that's focused more specifically on returning to paid work has found that people aren't always able to return to their pre injury levels of employment if at all. The statistics that the return to work rates that studies report range between about 40% to 67%.

So there are likely quite a few factors that contribute to people not being able to return to work.

Some of this is around the readiness to return to work, so some people return a little bit prematurely out of fear of losing their jobs, so concerns around job security and then they end up actually getting burnt out, so it's a bit too premature in their, along their course of recovery.

On the other hand, some people aren't able to return soon enough and then experience feelings of failure around this.

There have also been factors within the workplace that have been identified, so just a general lack of understanding of ABI in the workplace and a lack of knowledge of how to accommodate people with ABI as well as discrimination and harassment, so this has led to people with ABI feeling stigmatised within the workplace.

So, research has found that participating in paid work is about much more than just security and income. There have been links between participating in paid work and the health and wellbeing of people with ABI.

In fact, work's been found to contribute positively to a person's life satisfaction, mental health, sense of personal identity and social connectedness.

So, I think it's important to consider the role of work when we look at the health and wellbeing of people with ABI, especially given that in this population, returning to paid work isn't always a feasible option.

Fortunately, there are still many ways for people with ABI to live productively, even when they aren't able to participate in paid work.

There is a limited amount of research that's explored the benefits of volunteering and other kinds of productive activities for people with ABI.

However, volunteering in particular may be a more appropriate alternative.

Interestingly, only one study to our knowledge has focused on people with ABI and the benefits of volunteering.

We'll explore this topic quantitatively in a group of 208 participants with traumatic brain injury and what they found is that engaging in volunteering led to improved psychological adjustment in this group.

Some of the benefits that they identified in the study include less physical/mental fatigue, greater motivation in general, more physical activity and fewer problems associated with depression.

To date, there are no other studies that have used qualitative enquiry to explore the experiences of people with ABI who are engaging in volunteer work.

While quantitative enquiry is also useful for measuring the benefits of volunteering and identifying important relationships and trends, using qualitative methodology to explore this topic is also a beneficial way of gaining new insights and perspectives that would add to the current body of knowledge.

So for this reason, we chose to focus the study on the subject of experiences of people with ABI, therefore the research question that informed our study was what are the experiences of people with ABI in volunteering roles?

To explore this research question, we selected a qualitative case study methodology.

This kind of methodology is well suited for exploring complex social phenomena in their real life contexts, in particular when it is difficult to separate the social phenomenon from the context that it's situated in.

We selected an exploratory collective case study design.

This type of case study design is well suited to exploring topics that haven't been explored extensively in the literature.

Generally, findings from an exploratory case study are used to gain an initial understanding of the topic and can therefore help to inform the direction of subsequent research.

We also selected a collective case study design.

This involved studying multiple cases across several different contexts and what this allows to do is to gain a broader understanding of the topic.

Before we began recruiting participants and collecting data, we gained ethical approval from the study, for the study, from the University of South Australia ethics committee.

We recruited participants through a volunteer-based NGO in South Australia, Adelaide.

The methods that we used to recruit participants included placing advertisements at the main office of the organisation, distributing fliers to members of the network who attended support groups and attending support groups and fundraising events ourselves to provide more information about the study to members in person.

Members were considered eligible to participate in the study if they had engaged in a volunteering role in at least the last 12 months, lived in metropolitan Adelaide or were comfortable to travel to the metropolitan area for interviewing, had the English and communication skills to participate in interviews, had experience in ABI at least two years prior to study commencement, had the capacity to consent to participating in the study and were over 18 years of age.

We also enquired about whether participants had a significant other or someone who was in touch with the person throughout the volunteering experience and who the person with ABI perceived to provide ongoing support in other areas of their daily life.

We were seeking the second person to act as a second source and to also participate in the study and one of the reasons we did this is because gathering data from another source assisted with triangulating the results, so this was one of the measures we used to improve the trustworthiness of the findings.

So following the recruitment process, four cases were included in the study that consisted of eight participants.

Our main method of data collection was semi-structured interviews with open-ended questions.

This allowed us to gather rich descriptions of participants' experiences.

Eight interviews occurred in the participants' homes and one occurred in the workplace where the community worker was based.

Two participants were interviewed twice, they required some additional time to answer all the questions, there was also one joint interview between two spouses.

These interviews were recorded and then later transcribed verbatim in preparation for the analysis of the data.

So we used thematic analysis to analyse the data within and across cases and this allowed us to identify the commonalities and differences between the different participants' experiences.

We used open coding initially to generate codes in the transcript data, we then later clustered this together based on their likeness and meaning in to what we called categories.

Initially, we analysed each of the cases separately and looked at the categories within each case to understand that case holistically, but also to see which aspects of the case were individual and unique from each other.

Also, after that, we generated themes by examining the categories across all cases and then that allowed the similarities between cases to emerge.

So the data revealed four main things that we associated with participants' volunteering experiences.

These things that we identified were spending one's time purposefully, being valued for your contribution, being part of society again and experimenting and contemplating the future.

We've used pseudonyms to report the findings of this study to maintain people's anonymity.

We've also decided just to exclude any identifying details of each case just so that we can mitigate the risk of people with insider knowledge being able to recognise any of the participants.

So the first theme, spending one's time purposefully included data associated with participants' experiences of finding a meaningfully productive way to spend their time again.

Participating in volunteering activities was a way for people to use their time with intent.

People identified that simply having an outlet such as volunteering prevented the alternative of having vast amounts of unoccupied time.

Some people expressed concerns about how this can affect their personal wellbeing.

John stated, I'd go crazy here. If I didn't do any volunteer work, I would just, look, I'd be a vegetable because I'd just be here Monday to Friday waiting for Emma to come home.

So adjusting to life following brain injury often involved finding other ways of being productive and taking up a volunteering role was considered just one way of remaining stimulated and engaged.

Participants also associated a volunteering role with greater flexibility and less work pressure when compared to a conventional employment role and they considered this as an important consideration for them when they were deciding to take up volunteering.

They also emphasised the significance of undertaking volunteer work that has meaning and is intrinsically rewarding.

This became more important in the volunteering role because of the lack of income accompanying the work being done.

Molly said, and this was something that circled back quite a bit in her interview, I think in the volunteering role, you're doing it, well, I'm doing it because there's a passion word again because I'm passionate about it whereas in working life, you do it because you've got to earn a living.

So the volunteering role had a very normalising effect as it provided something for participants to organise their day or week around when they were unable to return to their previous employment roles.

Indeed, productivity does often serve this function in our lives. It provides some structure and routine for us to work around.

Having some form of productivity in one's life was seen by participants as more than just a necessary part of surviving or existing in society.

People identified how important it is to their mental health and wellbeing to include productivity in order to feel stimulated and to feel engaged and to feel like they were spending their time doing something valuable and worthwhile.

The second theme being valued for your contribution included data associated with participants' experiences of feeling appreciated for the work that they were doing.

Volunteering was a way for participants to make a meaningful contribution and this led to feelings of increased self-worth.

Participants noted that they had increased confidence and they felt a sense of achievement by demonstrating competence in their volunteering roles.

These gains came about when they were able to appraise their own performance and contribution.

So, for example, Will said, it gives you a feeling of accomplishment, yet because you think, I had a hand in doing that. You mightn't have done it all by yourself, but I had a hand in it and that really counts, it really makes a big difference.

In Will's case, the confidence that he gained from his volunteering activities led to him pursuing other opportunities at university.

His paid carer observed that it's a gradual process. You have to build the confidence to reach that next level in your life.

If there's no confidence, nothing will happen if you're scared to go in to the world, so for him, volunteering got him the boost, the confidence again.

Participants also reporting feeling more confidence when they received feedback from others in the volunteering context, that assured them that they were doing well in their role.

On the other hand, some people were negatively affected when they felt unappreciated within their role or when they felt like they were not given adequate opportunity to fulfil their potential.

John described feeling undervalued when his suggestions and contributions were not taken seriously.

He said, I'd just like to be appreciated for the intellect, for some intellect that I've got and if I'm making a suggestion, I'd like somebody to listen to me and either act on it or discuss it.

So, volunteering has great potential to act as a stepping-stone in vocational pursuits. It reminds people with ABI of their potential and their capabilities, rather than focusing on their deficits.

This can be especially valuable for people who've undergone significant changes as a result of their ABI that may lead to them feeling self doubt in regard to their abilities.

This finding also highlights just how variable the experiences can be and how it can be impacted so much by the social environment in the volunteering context itself.

So, the other people in the volunteering environment can be quite pivotal in producing a meaningful and confidence boosting experience for someone with ABI.

The third theme, being part of society, again included data associated with participants' experiences of finding community and providing a source of socialisation in their lives.

Feeling socially excluded wasn't an uncommon experience for people with ABI.

Volunteering was described by participants as a tool for overcoming this barrier to inclusion in society.

Volunteering acted as an opportunity to interact with other people socially and to gain a sense of belonging to the wider community.

Building connections and relationships in this capacity gave rise to greater feelings of social inclusion.

So, Mark stated, social inclusion, being a person who is socially isolated, giving myself the opportunity to be socially included and spending a few hours at a time with people who are generally positive and happy and with the same focus on a given day, is a treat.

Volunteering with or around other individuals with similar experiences related to having an ABI was also emphasised as a meaningful component of the social interaction.

Hearing from others with similar experiences lessened people's feelings of loneliness that accompanied coping with the daily challenges of ABI, of living with an ABI.

There was also a sense that participants had entered a space where they felt that they could be understood, supported and free of judgment and discrimination.

So, Molly touched on this when she said, it made me feel like I wasn't a freak, that there are other people who are going through the same stuff.

When Molly's partner, Tim described his observations of her in her volunteering role, he noted that her lived experience of having an ABI was actually an asset that she could draw on when acting as a volunteer.

She's got an experience that she can pass on to other people and she feels she connects more with them that way than a professional standing up there.

She's got some of the answers and they can relate to it and see it.

So, the social aspect of volunteering can in many ways be compared to the social benefits of going to work. While building relationships in the workplace may seem like something we do to achieve better outcomes in our jobs, and it certainly does facilitate that, it's also one of the ways that going to work that regularly benefits our mental health and wellbeing.

Those whose volunteer roles involved working with or around other people with ABI also reported how mutually beneficial they found it.

On one hand, they felt that their lived experience of having an ABI better enabled them to help others going through the same struggles.

On the other hand, it also enabled them to come to terms with their own losses and the challenges that they continue to cope with whilst feeling supported by others who have shared the same experience.

The fourth and final theme, experimenting and contemplating the future, included data that was associated with participants' experiences of learning about how they wish to engage with productivity in the future.

Volunteering allowed participants to contemplate the impact of living with an ABI on their future, including the effect on their work aspirations.

Volunteering was seen as a first step toward potential employment by providing the opportunity for participants to test their new work capacity through experimenting with how much work they can manage.

Molly reflected on the demands of her volunteering role.

Tim will often say, all of these hours that you put in and do all that you do, why don't you try and go back to work?

But I honestly don't think that I could, I don't know if that's a confidence thing or if I'm just being realistic about what I can capably do. I think I'm just being realistic.

For Mark, volunteering was seen as an important precursory step towards paid work by gaining and demonstrating work experience.

In particular, Mark identified the added difficulty of being away from employment or any productive roles during his initial period of recovery following his ABI.

He said, if I could prove a little bit of consistency and negotiate with someone six to 12 months down the track, prove some consistency that I might be worth a reference, that would be all I ask because I volunteer. Hey, it's a volunteer situation, I don't have to be there, but if somebody could testify to my worthiness, trustworthiness, reliability, the things which are positive, I think that's a fair trade-off in that situation.

Significant others and carers also discussed the type of support that they provided to assist with maintaining the volunteering role.

This included the importance of providing moral support and encouragement as well as knowing when to step in and when to step back, how much support is needed.

Will described Dunika's support during a difficult time when his role ended abruptly for reasons that were beyond his control.

He said in reflection, we talked, as when I was going through that period, every morning when she got here, we'd always have a bit of a debrief and she listened to what my inner feelings were. She would just listen to what I felt. It just felt so great to have somebody to talk to who was also so willing to listen and give advice as well.

So the majority of people with ABI do experience changes that affect their ability to participate in work or other productive roles.

Often, it is difficult to predict how and to what degree this will be affected. The only way to truly know is to experiment by doing.

However, experimenting within a paid role can be perhaps more stressful due to expectations around productivity and feeling more responsible for ensuring certain outcomes.

So, this may leave people with ABI with less room to focus on their own recovery and self-discovery within the productive role.

Participants identified that a volunteering role provided them with a space to learn about what they can do and where they may need additional supports and modifications when engaging in productivity in the future.

Significant others and other advocates or support persons can also be very helpful in facilitating this process by providing support when needed.

However, there are also times when the right kind of support looks a little bit more like stepping back and allowing the person with ABI to take the lead.

So, in summary of these thematic findings, we found that each person with ABI had a very unique and individual experience with their volunteering role.

However, we did also see some commonalities that came through.

Volunteering acted as an opportunity for people with ABI to regain many aspects of their lives that may have been either disrupted or lost.

It provided them with a platform to reengage in productive roles that have meaning and contributed positively to the process of reforming personal identity following the injury.

Given that people with ABI are not always able to return to paid employment, volunteering is an alternative, which may cater more appropriately to the mixed needs, excuse me, and capacities of people with ABI. It has the potential to be used as a means to assist them along their recovery.

So, the findings in this study do complement some research that has also explored similar and related topics.

Our study identified the importance of a supportive volunteering environment that included people who encouraged the volunteers with ABI and identified how this contributes to the self-image of participants.

In a study conducted by Petrella that explored the perspectives of people with ABI engaging in productive roles in general, it was identified as well that the support and feedback that they received from others were factors that influenced their motivation and engagement in productive activities.

Secondly, participants in the current study also expressed the importance of having the opportunity to build relationships and to gain a sense of social belonging and they reported that this factor contributed to the meaning behind their volunteering activities.

Other research, quite a bit of research, has also highlighted the significance of having the opportunity to socialise following an ABI.

Martin found that individuals with ABI undergoing goal directed rehabilitation identified their priorities in goal setting to revolve around being more connected in the social context of their lives and feeling part of things.

In another study conducted by Douglas, regular participation in community led leisure activities led to improvements in measures of social integration and mental health.

In interviews, participants in the study who engaged in the leisure activities regularly described experiencing a more positive effect on sense of self and confidence, feelings of happiness and belonging, achievement and the experience of friendship.

Lastly, the current study also identified how volunteering can contribute to the process of adaptation in which people with ABI adjust to living with the effects of their injury, particularly in relation to productive roles.

In the study conducted by Petrella, participants also identified the need to experiment within their productive role to facilitate gaining and understanding of their new work capacity as well as just adjusting to their brain injury all together.

So, in summary, when we reviewed our study findings in the context of other research that explored similar related topics, we found that the literature has largely focused on people with ABI and their general experience of returning to productive roles as well as their experience of participation in society more broadly.

However, our study has contributed to the current body of knowledge by focusing more specifically on volunteering as a means of providing people with ABI with numerous opportunities that are not necessarily as easily satisfied by other types of activities in daily life.

So if we once again zoom out and look at the bigger picture, what do these findings mean?

We know that introducing productivity through volunteering is beneficial to the longer-term recovery and reintegration of people with ABI.

However, the focus of rehabilitation services often lie in instrumental activities such as self-care activities.

Quite often when patients are able to complete these more essential activities with greater independence, this acts as a marker that facilitates discharge from inpatient settings.

Early rehabilitation services available for people with ABI, they're often influenced by financial pressures and cultural expectations experienced by clinicians.

In these settings, goal setting tends to be more driven toward improving physical functioning and focusing on more realistic progress that can be feasibly achieved within that timeframe.

It appears that the need for people with ABI to reengage in productive roles is difficult to address at such an early stage and this is also due to the fact that for many people with ABI, they may not be ready to explore productivity during that very early period, it might simply be too overwhelming.

Despite this, community rehabilitation services for people with brain injury are often associated with issues of cost and can be quite difficult to access particularly if someone is relying on the public health care system.

The findings certainly do indicate that follow up would be beneficial to support people with ABI to reengage in productive occupations.

This should include consideration of volunteering as an alternative to paid work where paid work is not a feasible option for the person.

So we identified several limitations to our studies.

We focused largely on the perspectives of individuals with ABI and their significant others, carers or support workers.

However, new insights would be gained by exploring the perspectives of individuals within the volunteering organisation as well.

Secondly, all of the cases included in the study were recruited in Adelaide, South Australia. It would be beneficial to repeat the study in places that have different geographical and socio-political characteristics and this could include larger cities, rural areas, other states in Australia and even other countries.

This would further our understanding of how the context influences the experience of volunteering following ABI.

Lastly, it would also be beneficial to continue quantitatively measuring the outcomes of engaging and volunteering, particularly based on the new light that has been shed by the findings in our study.

This could include measures of mental health, social connectivity, physical activity, community integration as well as individual perceptions of confidence and competence.

Lastly, I'd like to acknowledge the following people and institutions for their contributions and support throughout this research study.

To the Summer Foundation and the Rotary Club of Kew for seeing the potential of the study and supporting its completion through the Allen Martin Research Scholarship in 2016.

We'd also like to acknowledge these institutions for altogether supporting research that aims to improve the knowledge and understanding of living with a brain injury.

To the ABI support network who assisted with recruitment and its members who participated in the study for openly and honestly sharing their stories and experiences in the hope that it will help others in their shoes.

To the University of South Australia for providing me with the opportunity to expand my educational horizons and to allow me to explore the world of research and science and to both my supervisors Dr Mandy Stanley and Dr Jocelyn Kernot for providing their guidance and insights throughout the entire process and supporting my growth as a young researcher and occupational scientist.

So that brings us to the end, I'd like to have some questions now if you have any.

(Applause):

Speaker: Thank you, Suzana, that was a lovely talk, I especially loved the happy pictures, it's a good thing to be looking at early in the morning, isn't it? It kind of makes you feel happy.

Can I just ask you a quick question first? Are you publishing your-?

SH: Yes, a good question, yes, so we are in the process of revising our manuscript, we have submitted it once, we have gotten some good feedback, so we're looking at revising that and resubmitting in the near future.

Speaker: My thoughts as I was listening to you, it would be lovely to have some published material that we as clinicians and stuff can use to support the work that we do.

SH: Absolutely, definitely.

Speaker: Okay, to the floor.

LS: My name is Lisa Sherry, I'm a rehab physician, I've got a horrible question for you, so this was sparked by the thought of the question that Molly asked herself, am I being realistic? Now I really would like to know a lot more about the people who you're interviewing because I didn't know if she was being realistic or not and I wondered if this was a group of people who could bring in paid work. I would have loved to have known a little bit more about their activity and participation in the research because I didn't know whether she was being realistic and it did make me wonder if the people who you were interviewing were the right group of people.

SH: Yes, yeah, that's a really good point and I can see how that thought would've come up., We did try to, I guess we were very mindful about how much information we gave away about participants. It is quite usual in case studies that we do give a bit of a background on people's contexts and we did have a bit of a summary of all the participants initially and it wasn't until the very I guess final stages of when we were looking and right before we were about to submit when we were just a bit concerned that the organisation that we recruited from, there's not, there are basically only two organisations like ABI support networks in South Australia and we were quite concerned that people within the support network who we recruited from are very familiar with each other, so ultimately, we decided that we needed to prioritise the anonymity of participants.

LS: Wouldn't that be a big statement, though? Would that be possible to kind of cover all of these people who were at this point?

SH: Yeah, I guess it depends, yeah, honestly, we didn't initially include anything about what their functional level is like, so that might actually be something that we look, now that we're revising the manuscript, that might be a useful thing to include because it is something that's more relevant I think to clinicians than to perhaps the other people with insider knowledge who may not necessarily be able to identify the participants in that way. So yeah, thank you for that, that's actually a really good point.

Speaker: The other thing I was thinking of though, Lisa when you were raising that is that it just also points to the fact that it's really important to have access to ongoing supports that might actually facilitate and respond to some of those things because I don't know how long Molly had been working in her volunteer role, but in fact, maybe that was such a huge shift from her, when she first started and that opportunity to go, actually, maybe I am doing so well in this, I could do more, but without any access to supports, you don't get that opportunity to ask, so I think that's another aspect to look at in terms of where do you go with this in the future?

SH: Absolutely.

Kayno: My name's Kayno, I'm an occupational therapist at the transition living centre. I realise how difficult getting residents in to volunteer work can be, I just wanted to kind of have an open discussion about if the participants you interviewed either suggested or talked about ways that getting in to volunteer would probably help them, so if there were things, were there therapists going along or what made the successful transition to a really successful volunteer and then employment and things like that?

SH: Yeah, it's a really good question, I think for the people who were included in the study, they were all part of the support network prior to their commencing the volunteering role, so I think for them in particular, I think that was a huge factor because they were already in a very supportive environment, they actually didn't have any support from clinicians, so their support was largely from the people within the volunteering organisation, so none of the people there were therapists, but they were all extremely well versed in ABI and in what sort of supports people might need. A lot of it was just moral support and encouragement and I think as well just trial and error, so I think a lot of, I think it goes back to those fourth theme around experimenting and trialling, it might be a bit of an iterative process for people to find what works for them and what's meaningful for them. I think clinicians, particularly people with an OT background, I think while we can be quite good at doing is setting goals with a person about what they're actually trying to achieve, but also finding that just right fit, so what is giving them a challenge enough, but then also what is not exceeding their challenge levels, and I think John did say that when he said, if you're not meeting that person's level of challenge, then they might feel a little bit placated or it's probably a little bit insulting and then you don't get that confidence from the volunteering which is one of the benefits, but then obviously, if it's too much, then it's not a sustainable role. So I think that's where clinicians can probably be very helpful in seeing, assessing what the person's limitations are, what their abilities are and making recommendations about what might be the right level of challenge for them, but as well I think it's just as important to understand what the person's values are and to try and find something that is actually meaningful for them and rewarding.

Speaker: I think the crux of the whole thing is if there's something, it's such a challenge, speaking from that.

SH: Yeah, exactly, yeah, and I think for many clinicians, that part about it being iterative process is a bit difficult because not a lot of the settings that we work in allow for that, often it's just a once off recommendation and then you may not actually be able to follow up with that particular person, but it depends on where you work, I think.

Q: Can I ask, excuse me, were the volunteering opportunities with other people with ABI, were they co-volunteers or were your clients in a situation with people who didn't have ABI just general volunteer agencies?

SH: Yes, it varied. So it was a variety, the people who were working with other people with ABI, that was predominantly around facilitating support groups. So one of the main things that the support network that we recruited from, that's one of the big things that they do is that they provide support groups that are run by other people with ABI, so that's why in this particular, for these participants who helped to facilitate those support groups, it was very helpful for them to be able to draw on their own experiences and I think for the other people, so the other people with ABI who attended those support groups, it was perhaps a bit more valuable because they felt like they weren't just being dished out advice from someone who doesn't understand the lived experience, exactly, there were also some people, like John volunteered at an op shop. I personally found it interesting that he was the only person who described feeling some form of I guess discrimination or being treated differently because I think his case was the only one in which people, he wasn't around other people with ABI.

Q: I have a client, too, in an op shop, she's a woman of 54/55, so most women of 55 who wouldn't be working in an op shop, but context to her being the only person with an ABI but with a whole lot of older people works beautifully for her because they're kind and thoughtful and it just works.

SH: Yeah, definitely and I think older people as well, they also understand a lot of that stuff around needing to accommodate for changes and occupationally as well.

Cathy: I'm Cathy from the Summer Foundation, I think it's picking up a bit of what Kay was saying, too, do you think we're saying maybe the goal, a person's goal isn't to volunteer and that sometimes as clinicians, we think of it that way, that's the goal, whereas you're trying to work out what's meaningful to the person which is what you were saying of value, what's important to them and some of that's what really came through to me in some of your slides and the talk, so if you've got that, then the volunteering is just that happens to be an activity to be able to achieve that, rather than thinking the goal is I've got to fill in my time or I've got to volunteer.

SH: Yeah, okay, I see what you're saying, yes.

Cathy: So the goal is I want to feel like I'm a valued member of society and I can do that in a whole bunch of ways and one way to do that is to volunteer.

SH: Yeah, definitely, yes, I see what you're saying, I agree with rather than having a goal that's to be able to volunteer.

Cathy: Three times a week because we all get fixated on what are we going to do and then we get caught up and that's even the same, what is it that we really want to get out of this and then volunteering might be the one way to achieve that.

SH: Yeah, that's a good point. I think it would be helpful if possible to include, in terms of goal setting, to look at both those things, if we're thinking about smart goals, in terms of making it specific and knowing if we've achieved that goal, so even though the outcome that we're searching for isn't just to volunteer because somebody could meet a goal to go volunteer three times a week like you say, but then still not feel like it's the right fit for them, but at the same time, if we don't have that qualifier in there, it will, it's also quite difficult to know that the goal's been met, so I think it's important to include both those aspects in the goal setting, both what it looks like, what you're physically doing, but also on a more psychosocial level, what you're trying to achieve out of it, so even something like to be able to go and volunteer three times a week in order to feel, etc, just my thoughts.

Heidi: I'm Heidi, a neuropsychologist, I've got a comment that in Melbourne, a lot of my clients do volunteer work and a lot of them try and get volunteer work probably for a lot of TAC clients as a step towards employment in not just fill in time, but to see how many schedule to attend to and an obligation to report and those sorts of things and practising work readiness skills, I guess, but it's actually not that easy to be a volunteer, there's so much paperwork and a lot of our clients have forensic history with drugs and alcohol to do volunteer work to recruit and I actually think it would be a really negative process and getting their feedback, sorry, you're not going to be able to do it because of your history, so they've not only got the ABI, they've got this history that's constantly chasing them and I find it's really hard and we end up doing things like working in an op shop which for a lot of our young guys, I don't want to work in an op shop, so it's really hard to find the match.

Speaker: The safer our world is getting, the more restricted it is, in the good old days, you could just wander down to your local primary school or something. In sort of keeping us safer and giving us all of those things, that's made it really, really hard to find opportunities to do things and it's such a struggle.

Heidi: It's almost as hard as actually getting paperwork.

SH: Yeah, that's what I was going to say, I wonder if it's even more difficult than getting a paid job or if it's a good imitation of what that process would be like, seeking paid work as well.

Q: Has anyone got grand ideas about finding volunteers that they can share that none of us know about?

Speaker: I find the volunteer resource networks and most of the local councils are really staying because at least then you know you're approaching organisations that are interested in volunteers and then in terms of overcoming the forensic side of it, I found sometimes that if you sort of sell it, well, this person is going to be coming with a support person, then for some people if they're willing to accept a support person and they need one, but then for

other people, they potentially could do the role independently in sort of reducing their independence.

Q: People who do not have an ABI use Seek volunteer section.

SH: Yes, true.

Speaker: Any other questions?

Well, thank, you very much, Suzana for this year's Breakfast Series and we look forward to seeing the publication.

SH: You're very welcome, yes, absolutely, I'll let you know as soon as I know. Thank you.

(Applause):

END OF TRANSCRIPT