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The experiences of adults with complex communication needs who volunteer

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Abstract

Purpose: The aim of this study was to explore the experiences of adults with complex communication needs (CCN) who engage in volunteering.

Method: In depth interviews were conducted with 24 adults with CCN who had worked as volunteers. Interview transcripts were analysed according to grounded theory methodology.

Results: ‘Control’ emerged as the most important factor determining the nature of the participants’ volunteering experiences. Two key strategies for enhancing control were the provision of augmentative and alternative communication (AAC) systems and appropriate support to volunteer. A theoretical model to account for the experiences of volunteers with complex communication needs is presented.

Conclusions: Adults with CCN who want to volunteer must have access to an effective communication system and appropriate support if they are to volunteer successfully for the benefit of themselves and others.

The experiences of adults with complex communication needs who volunteer

Introduction

Formal volunteering is a common and highly valued activity in modern society [1], which results in benefits for individuals, organisations, and societies at large [2, 3]. Individuals who engage in formal volunteering do so in not for profit organisations for no financial payment and in positions that are designed for volunteers only [4]. Formal volunteering is different from informal volunteering (e.g. watering a neighbour's plants or collecting mail) and from paid work. It is a meaningful societal role in its own right that adults with and without disabilities are motivated to fulfil [5, 6].

Motivation to volunteer

The results of recent studies [5, 6] confirm that many adults with complex communication needs (CCN), who have little or no functional speech, want to volunteer, for the same reasons as adults without disability. That is, they are motivated to volunteer across a variety of roles [7] for their own benefit and for the benefit of others [8]. Indeed, some adults with CCN are already volunteering. The International Society for Augmentative and Alternative Communication (ISAAC), for example, has successfully recruited individuals with CCN into volunteer leadership positions within the organisation [9]. However, adults with lifelong disability, including those with CCN, are generally underrepresented in the volunteering workforce [10, 11]. Adults with disability are often perceived by those without disability to be recipients rather than providers of community service [6, 7], and so are not afforded the same opportunities to volunteer as their peers without disability. Consequently, many adults with CCN do not have access to the benefits that come from volunteering [2].

Benefits of volunteering

Volunteering results in benefits for adults with and without disability [2, 10]. Choma and Ochocka [11] reported on a study in which 226 adults with physical, intellectual, and sensory disabilities engaged in formal volunteering over a two year period. The participants said that volunteering increased their levels of independence and self-confidence, helped them to develop a greater sense of responsibility, and provided them with opportunities to develop new skills and to meet new people. In addition, volunteering enabled them to be involved in their community, to be the providers rather than recipients of community service, and to improve their overall well-being and quality of life. Volunteering may therefore be an effective means by which to address common challenges for adults with CCN such as loneliness [12] and low levels of community participation [13]. In addition, volunteering may be a desirable vocation for some adults with CCN who are unable to gain paid employment or who have retired from work [5]. However, just as adults with CCN face barriers to their participation in community and employment settings [14], so too are they likely to face barriers when volunteering.

Barriers to volunteering

Choma and Ochocka [11] identified several barriers which reduced the opportunities for adults with disabilities to volunteer. These included: (a) a tendency for organisations to underestimate the participants' abilities; (b) difficulties matching the volunteer roles with the participants' changing needs; (c) staff not feeling adequately trained to support individuals who had mental health and behavioural issues, hygiene issues, or difficulties with literacy; (d) difficulties finding meaningful roles that suited each participant's unique abilities; and (e) issues of access for individuals with physical disability using powered mobility aids. Bruce [6] identified similar issues including: (a) a lack of volunteering opportunities, (b) inaccessible buildings and transport, (c) low levels of literacy amongst volunteers, and (d) disabling attitudes

amongst staff in organisations as key barriers to volunteering for adults with lifelong disability. Although having a low level of literacy was identified as a barrier to volunteering, it is not clear from these studies what impact having complex communication needs has on the experiences of volunteers. Given that communication is fundamental to seeking and engaging in volunteering work [15], adults with lifelong disability who have little or no functional speech are likely to face additional barriers in their attempts to volunteer.

Communication

Staff who support adults with lifelong disability to volunteer confirmed that having communication difficulties was a common barrier to adults with CCN volunteering (Balandin, Llewellyn, Dew, and Ballin [15]). In particular, the impact of having communication difficulties was evident in roles that required interaction with other staff or members of the public. Balandin et al. emphasised the need for adults with CCN to have access to augmentative and alternative communication (AAC) systems such as spelling boards and speech generating devices in order to volunteer successfully. However, little is known about the specific communication barriers that exist for volunteers with CCN, and the extent to which AAC systems can be effective in supporting their successful participation in volunteering. The aim of this study was to explore the experiences of adults with CCN who had engaged in volunteering in order to identify strategies for promoting and supporting those who want to volunteer.

Method

Ethical approval

This study was approved by the University of Sydney Human Research Ethics Committee and the ethics committees of two non-government disability service providers that assisted with recruitment.

Recruitment

Participants were recruited via advertisements and information sheets distributed by speech pathologists and staff in disability organisations who worked with adults with CCN. A full text version and an illustrated version of the information sheet were distributed in an effort to accommodate the differing literacy needs of potential participants. Individuals who expressed interest in the study were asked to sign a form and to correctly answer four questions about the study to ascertain that they were able to provide informed consent [16].

Participants

The participants were 12 women and 12 men, between the ages of 20 and 70 years, from four states across southern and eastern Australia. All participants had CCN and had engaged in formal volunteering with a not-for-profit organisation on one or more occasions for a minimum of one hour, in their adult lives. Overall, 14 were currently engaged in volunteering at the time of the study and the remaining 10 had volunteered in the past and were not currently seeking voluntary work. Their volunteering roles included serving on committees and boards of disability organisations, broadcasting on community radio, volunteering at the local hospital or a religious organisation, presenting to others on disability related issues, mentoring others with disability, and volunteering in the performing arts.

Eighteen participants used AAC systems (manual boards, communication books, and speech generating devices) as their primary mode of communication. The other six participants used AAC in addition to their natural speech. A summary of the participants including their communication systems; their education, volunteering, and work histories; and their living and support arrangements is provided in Table 1. Pseudonyms have been used and only broad descriptions of their demographic information are provided in an effort to protect confidentiality.

[Insert Table 1 about here]

Researchers' backgrounds and beliefs

The interviewer and first author is a speech pathologist experienced in working with adults with CCN who use AAC, and who has engaged in both formal and informal volunteering throughout his life, with mostly positive outcomes. The second, third, and fourth authors are all highly experienced in working with adults with lifelong disability. All authors advocate that individuals with lifelong disability have the right to participate in the same way as their peers without disability, and that participation benefits both individuals and society. The second author, who audited the analysis, is experienced in conducting qualitative research involving individuals with lifelong disability.

Materials

Interviews were recorded using a digital voice recorder and NVIVO8™ software [17] was used to assist with storage and coding of transcripts.

Process

Interviews

Two semi-structured interviews were conducted with each participant at times and a place of his or her choosing. The purpose of the first interview was to explore the participant's experience of volunteering. The second interview was used to verify and elaborate on the findings of the first interview and to explore issues that had been raised by other participants. A written summary of the first interview was used to facilitate this process [18]. Interviews lasted approximately 90 minutes and were digitally recorded for transcription purposes. An interview guide (Appendix 1) was used to ensure a wide range of issues were raised and discussed.

Analysis

Analysis was conducted using grounded theory methodology [19]. Following each interview, the recording was transcribed in full and preliminary analysis conducted to inform the development of questions for subsequent interviews. The constant comparative method [20] was used to identify similarities and differences in the data at all stages of analysis, which included open coding, axial coding, selective coding, and theoretical sampling. Coding decisions, issues requiring further exploration, and reflections on the emerging theory were documented using written memos [19].

Open coding was used to identify discrete incidents, events, and other phenomena in the data. A line of text, for example, in which a participant explained that he volunteered in order to bring happiness to other people, was coded ‘helping and bringing happiness’. Related codes were then grouped to form sub-categories, and eventually categories. The code ‘helping and bringing happiness’, for example, was grouped with related codes to form a sub-category labelled ‘wanting to make a difference’, which was in turn grouped under a category labelled ‘motivation to volunteer’. The coding process is illustrated in figure 1.

[Insert figure 1 about here]

An axial coding paradigm [19] was used to define the *causal conditions* that gave rise to each category (phenomenon), the conditions or *context* within which it occurred, the *action/interaction strategies* used by the participants, the *intervening conditions* which influenced the choice of actions and strategies, and the *consequences* of those actions and strategies. Selective coding was then used to identify the single most important category and to systematically relate it to all other categories. Through this process, a grounded theory emerged to account for the participants’ experiences of volunteering.

Further interviews were conducted in order to complete and validate the emerging grounded theory. The process, known as theoretical sampling [19], involved systematically assessing the extent to which the theory accounted for the experiences of each participant. Interviewing ceased when the theoretical saturation of each category was achieved. That is, no new relevant data was emerging, all paradigm elements were accounted for, and the relationships between categories were established and validated [19].

Credibility

Three methods were used to ensure credibility of the data and the first author's interpretation of it. First, as noted previously, participants were asked to review summaries of their first interviews in order to identify errors or omissions [18]. Second, investigator triangulation was used to increase confidence in the accuracy of the researcher's interpretation during all stages of coding. The second author reviewed the original transcripts and the first author's coding to identify discrepancies, errors, and misinterpretations in the data and coding. Differences in interpretation were resolved through discussion and amendments were made accordingly [21]. Third, the memos written throughout data collection and analysis formed an audit trail, enabling the second, third, and fourth authors to review the process of enquiry and to assess the extent to which the theory was grounded in the data [22].

Dissemination

The first author sent the participants a plain language written summary of the research outcomes at the end of the study. An audio version on CD was also provided to participants who preferred not to read, but to listen to the information summary. In addition, the first author offered to discuss the outcomes of the study with the participants in person with participants who lived in the same city or via phone or email if participants lived interstate.

Results

Six sub-categories were identified during open and axial coding. These merged during later analysis to form three categories labelled 'control', 'that is life' and 'making a difference'. 'Control' was identified as the single most important factor explaining the experiences of the participants, and was thus labelled the core category.

Control

Control affected every aspect of the participants' experiences of volunteering. Through gaining and exerting control, participants were able to move from situations in which they aspired to volunteer but felt unable to do so, to situations in which they overcame barriers and volunteered successfully, benefiting themselves and others. This process is represented in figure 2 as the transition from the category labelled 'that is life' to 'making a difference'. The effect that control had on the experiences of the participants is best explained through a detailed description of 'that is life' and 'making a difference'.

[Insert figure 2 about here]

That is life

Peter, who volunteered at a community radio station, was asked how he felt when volunteering did not lead to paid work, despite his hopes that it would. 'That is life' he responded. Peter, like many of the participants, indicated that he regularly encountered barriers in his everyday life that were beyond his control and made it hard for him to participate in activities such as volunteering. His statement captured the pervasive nature of three key barriers to volunteering reported by the participants, and was therefore selected as the label for the category. The three barriers were (a) communication barriers, (b) participation barriers, and (c)

the need for appropriate support. Control determined the extent to which participants were able to address these barriers in order to engage in volunteering.

Communication

Communication was a barrier for all participants in their attempts to volunteer. Participants who had less effective communication had less control and were more reliant on other people to help them to find voluntary work. Amy, for example, who used a communication board, said that she wanted to seek volunteering opportunities independently, but that communication was too great a barrier.

INT: Why can't you find other volunteer work yourself?

Amy: Hard.

INT: Why is it hard? What makes it hard, in your words?

Amy: Because it is so hard.

INT: So what things make it hard?

Amy: Need help.

Emma, who also relied on support staff to organise her volunteering, said that she was not volunteering at the time of the study because staff did not have the time to assist her.

'...at the moment, the staff are too busy to do it'.

Because of their communication difficulties, Amy and Emma did not have control over whether they volunteered, and subsequently had fewer opportunities to volunteer.

For those participants who were volunteering at the time of the study, having CCN made it hard for them to carry out their volunteering roles. Cathy highlighted the challenges she faced

in volunteering on several committees.

‘Sometimes the people don’t understand me, what I’m saying, and I have to say it again.... It takes a long time to talk to people too’.

Carl, who combined natural speech with the use of a speech generating device, said that interactions were difficult when individuals pretended that they understood his speech, even though they did not.

‘I know when people, I know when people don’t understand. It’s just, I feel it really, I can tell, I don’t know how but I know. Perhaps body language... I hate that, I really do’.

Communication breakdowns such as these were frequently reported by the participants and highlighted their need to have effective AAC systems in order to volunteer successfully.

Participants who had effective AAC systems were able to exert control over their volunteering, despite having CCN. Dawn and Bruce, for example, were independent in fulfilling their roles on boards and committees which required high level communication skills. Luke explained the importance of having his speech generating device when presenting disability awareness workshops.

INT: How important is having the [device] to your volunteering?

Luke: Very, very. If I didn’t have a machine to talk it would be bloody hard and I wouldn’t.

However, despite the benefits associated with using AAC, participants also noted that gaining access to appropriate systems was often difficult, thus reducing their level of independence and control when it came to volunteering.

Several participants reported that they did not have the AAC systems and support they needed in everyday life, which in turn impacted on their volunteering. Eric, for example, was not

able to use his new speech generating device because of a lack of appropriate support. Instead he used his communication board.

INT: Have you used both your device and your board when volunteering?

Eric: Yes.

INT: Do you find that interacting, working with other people, is easier when you use one or the other [i.e. speech generating device or communication board]? Do you prefer to use on or the other when talking with people?

Eric: My board.

INT: I am really interested to know why you prefer to use your board.

Eric: I need a lot more training.

Lisa, who was using a manual board, recounted that her speech generating device had ‘broken’ and had not be replaced because of a lack of ‘money’. Without appropriate AAC systems, the participants had less control over their voluntary work and were less able to address the participation barriers they faced in their attempts to volunteer.

Participation barriers

Participation barriers were frequently reported by the participants. The greater the participation barriers they faced, the less control they had over their volunteering experiences. In some cases, gaining access to volunteering workplaces was a barrier to their participation. Gary, for example, arrived at his local church ready to volunteer, only to discover that he could not access the office in which he was supposed to work. Jeff spoke of the dangers associated with inappropriate access in the hospital in which he volunteered:

‘The public lifts are still, their doors close too fast. I broke three lifts on different occasions because their doors close so fast. ‘

Carl suggested that members of the community are generally unaware of access issues and the effect these have on the participation of individuals with physical disabilities.

‘Some people don't see steps or a hill because it is normal to them... You just walk up. I can't’.

Problems with access meant that fewer volunteering opportunities were available to the participants, which, in turn, reduced their independence and control over what they did as volunteers and where they worked. Those who had effective communication skills were in a better position to identify and resolve these barriers than those who did not.

Several participants identified transport as a barrier to their volunteering. Carl was forced to wait one and half hours for an accessible train in order to get to a committee meeting.

‘It shouldn't happen but it does’.

Peter resorted to leaving a CD of his pre-recorded radio programme at the station because he found accessible taxis were too unreliable.

‘I could not run late.... I did it all at home first.... I did leave the CD at radio’.

However, not all participants reported problems with transport, as indicated by Anne.

INT: Some people have suggested things like transport can be a bit of a barrier or challenge. Would you agree with that?

Anne: I have good taxi.

Similarly, participants who accessed transport through a day service also said that transport had not been a barrier to participation in volunteering.

INT: Has transport been a problem [when volunteering]?

Jack: Gesturing disagreement.

INT: Is that because you organise transport through here?

Jack: Gesturing agreement.

In this way, access to transport determined the extent to which participants had control over their volunteering.

Costs associated with volunteering had a similar determining effect on volunteering for some participants. Emma raised her concerns regarding the cost of taxis.

INT: What would be the main concerns if you had to get taxis?

Emma: They don't come on time.

INT: Yes, anything else?

Emma: Probably the money, if you have to go a long way.

Dawn noted that increased petrol prices had impacted on her ability to volunteer.

'It's costing \$15 a week more. Once it didn't seem to matter, but ...petrol is now a consideration'.

A small number of participants, including Glen, volunteered with organisations that covered their transport costs.

'With [organisation's name withheld] you get free transport and a carer'.

These participants indicated that this was vital in enabling them to take on the volunteering roles.

They also noted that covering these costs made them feel valued and that it was appreciated, as

Dawn explained:

‘One person asked me to speak at their church. It was in [location withheld]. They put me up, fed me, and gave me \$100. I really appreciated it’.

Although all participants indicated that that they felt their work was valued, most had encountered people who had negative or disabling attitudes at some point when volunteering, as Tina explained.

‘People sometimes think we’re not capable to do a lot’.

Emma found it difficult to find voluntary work in preschools because of negative attitudes.

[It took] a couple of months [to find voluntary work] because they thought that I would be more work for staff.... I said what I would like to do and also they were worried that they would have to do work for me and it would take them away from their work and we assured them it would not be the case.... I suppose they didn’t know what was involved with me going there.

In this way, negative and disabling attitudes and misconceptions limited the volunteering opportunities available to some participants and even decreased their motivation to volunteer.

Peter described the barriers he faced when he attempted to compile and sell a CD to raise money for a disability organisation.

Peter: The [organisation name withheld] was not interested at all.

INT: So that was a barrier, because you had a great idea and you were willing to put in the energy to make it happen?

Peter: Big.

INT: Was it frustrating?

Peter: Gesturing agreement.

INT: Did it evoke any other feelings?

Peter: Give up.

INT: Give up. Yeah, it made you want to give up?

Peter: Gesturing agreement.

However, Emma said that she saw situations in which she viewed attitude barriers as opportunities to change individual's perceptions.

INT: [Are there] any other barriers or things that make it difficult to volunteer?

Emma: I can't think of any.

INT: Good. Can I run a couple [of suggestions] by you that other people have brought up? [the] idea of [negative] attitudes?

Emma: Yeah but that's why we're there.

Regardless of the different ways in which participants perceived the barriers they faced when seeking and engaging voluntary work, they all agreed that having access to appropriate support was imperative for having control over their volunteering work.

Support

Several participants spoke of the importance of having support from family and friends when addressing the communication and participation barriers that came with volunteering.

Dawn, for example, described the hardship she had endured due to not having a partner to provide her with emotional support when volunteering became stressful.

Dawn: It's very, very hard coming home and having no one.

INT: Do you mean in terms of, for support, to deal with...

Dawn: Both, and no one to take mind off it.

Emma, when asked to comment on Dawn's statements, responded empathetically:

INT: ...[Dawn] was saying that one thing that makes it hard to volunteer is that she doesn't have someone to go home and talk to about it.

Emma: That would be difficult.

INT: Yes.

Emma: Whereas, I'm very lucky I've got someone to talk to.

Equally important was the role of staff in providing formal support to the participants in their efforts to volunteer.

Several participants highlighted the ways in which staff had ensured that they remained in control of their volunteering, despite requiring support. Anne, for example, indicated that staff had ensured that she was present when they made phone calls on her behalf seeking voluntary work, so that she could make informed decisions about her volunteering.

Anne: I am there with them.

INT: Okay. So if they're making phone calls or organising things, you'll be there to make sure everything is okay and [named withheld] will ask you are you happy with this and you'll answer? Is it that sort of thing?

Anne: Gesturing and vocalising agreement.

Lisa had also been present when staff made phone calls on her behalf to organise volunteering, and had also been encouraged by staff to write a volunteering goal in her service plan to ensure that adequate support time was allocated. Emma spoke of the ways in which staff had tailored their level of support to meet her individual needs.

‘The staff are really good here and they are very understanding. They ask us what I’d like to do and I think that my needs are different to most of the other individuals here and I need to be more occupied’.

However, despite recounting positive experiences such as these, several participants were critical of the amount of support time available to them. They noted that decisions made about the level of formal support were often outside of their control and limited their opportunities to volunteer.

Jack, for example, was forced to reduce his voluntary work by half, due to restrictions on the amount of support time available. During the interview, he asked a member of staff to explain on his behalf.

Staff member: He enjoyed it but he had to give it up because it got too big a job and he didn’t have the spare time to go to the movies or to go out and do his banking or to do some of the personal things that he wanted to do because he was too busy doing the volunteering jobs....They’ve got four hours a day: like, it’s fairly limited. Instead of using eight hours in two days for his volunteering, he decided to keep four hours for another activity.... It wasn’t too hard or difficult, the times or anything like that. It was just um, the days.

Tim suggested that support provided to adults attending day services had decreased in recent years, due to increased demands on staff.

‘[In the] old days (there) was more time. Not like now’.

Peter was emphatic when asked to comment on the support available at his local day service.

INT: What are your thoughts on the level of support provided through the [name of day program withheld]?

Peter: I am sorry to tell you this: Shit.

For the majority of participants who relied on staff in order to volunteer, a lack of support was disempowering and prohibitive. Often, participants had little or no control over staffing arrangements and policies, and those who did not have effective communication were in a poor position to advocate for change. Consequently, communication barriers, participation barriers, and a lack of support combined to limit their control over decisions of if, when, and how they volunteered. However, with appropriate AAC and support, participants acquired the control necessary to move beyond these barriers to experience the benefits and success that came through volunteering. This transactional process is illustrated in figure 2 as the movement from the category ‘that is life’ to the category of ‘making a difference.’

Making a difference

The participants expressed a strong desire to help themselves and to help others through their volunteering. That is, they were committed to ‘making a difference’. This category emerged rapidly during analysis, reflecting the complex interaction between the themes expressed in three sub-categories: (a) the participants’ motivations to volunteer, (b) the benefits that resulted from volunteering, and (c) the extent to which the volunteering was a success.

Motivations to volunteer

For most participants, their desire to help other people was their main motivation for volunteering.

‘If I can help one person I’m happy’. (Carl)

‘I just love the music, plus the faces on the people too, they light up’. (Scott)

Participants who presented disability awareness workshops perceived that they were helping by changing people’s attitudes and perceptions.

‘I love helping people, to educate people, and to be with different people, so that they know that just because individuals have CP that they’re not stupid’. (Emma)

The motivations of the participants reflected a collective sense of community spirit and responsibility, and a strong desire to make a positive contribution through volunteering, as Glen explained:

‘I enjoy contributing to society and things around me’..

In addition to helping others, some participants also volunteered in order to achieve personal fulfilment and development. Sue was motivated to volunteer in order to get out of her group home and into the community:

‘...mostly I want to get out in the world.... I want to get out of here, get out into the world and do something’.

Several participants, including Cathy, wanted to meet new people through volunteering.

‘I wanted to get to know the people too’.

Beth used volunteering as a stepping stone towards paid work.

‘For me it was more about using it to make a step towards employment...’

Whatever their individual motivations for volunteering, all participants were very clear about why they wanted to volunteer and the benefits that they hoped to achieve for themselves and others through their work.

Benefits of volunteering

The participants' volunteering efforts led to many benefits for other individuals, the organisations in which they volunteered, and their communities. Emily spoke about the impact that she had on the life of a young girl with cerebral palsy, through her role as a mentor.

There was a parent at the camp who didn't think that her daughter would be able to use a power chair and after she saw me she is going to enquire about getting a power chair for her daughter

Glen explained how his unique life experience was particularly beneficial to the disability organisations in which he volunteered.

INT: Do you think there is anything different about your volunteering work to others?

Glen: My experiences and insight... I have had cerebral palsy since birth.

INT: Okay. So why do you think organisations ask you to volunteer? What is it that you can provide that they're seeking?

Glen: The experiences: ...coming to terms with cerebral palsy.

INT: What about organisations wanting to move forward, wanting to do things better.

Glen: Some guidance.

Tina hoped that her volunteering work would result in benefits for members of the wider community.

'I like to hope those people will go out in the world and make it better for someone else'.

In most cases, the desire to work for the benefits of others was the participants' key motivation to volunteer. However, the participants also identified a range of personal benefits they received through volunteering. The majority of participants mentioned the opportunities to meet new people that came from volunteering.

‘You find people who have your interests and values. You can also find the very few individuals who will take the time to be your friend’. (Dawn)

Volunteering had also helped some participants increase their confidence and self esteem.

‘I feel good about myself, because I am using my brain and experience’. (Glen)

‘I didn’t used to talk at the meetings but now I’ve started to talk more at the meetings’.

(Cathy)

In addition, several participants noted that they had developed their communication skills through volunteering.

‘I think my communication skills got better’. (Tim)

‘[I] learned how not to look at [my] keyboard [when doing presentations]’. (Luke)

The majority of participants had developed skills through their volunteering, that were of value to the organisations in which they worked, and potentially valuable in helping them gain paid work. Glen, for example, had developed a unique set of skills through volunteering on boards and committees.

INT: Can you give me an example of some of the skills you’ve developed through your role?

Glen: How to read financial reports and understanding how large organisations work.

Bruce and Laura commented specifically on the benefits of volunteering in helping them to gain paid work.

‘If I hadn’t been working on volunteering boards I guess I wouldn’t be working for [company name withheld]’. (Bruce)

‘I started my career as a volunteer and that is how I built my skills and experiences’.

(Laura)

However, for other participants, the key personal benefit to come from volunteering was the opportunity to expand their horizons and knowledge of the world.

‘It’s about expanding your knowledge’. (Dawn)

‘[Through volunteering] I learned how [other] people live’. (Craig)

For Emma, volunteering helped define her sense of self.

INT: What impact has volunteering had on your life?

Emma: It’s been a great experience to be able to educate people.

INT: Do you think it’s had a direct impact on your life, the fact that you’ve educated people?

Emma: I think that’s what I need to do. That’s my role in life.

For all participants, the benefits to result from volunteering contributed to their sense of satisfaction and success in their voluntary work.

Successful volunteering

All participants described their volunteering as successful, regardless of their differing experiences and outcomes. The fact that they felt that they made a difference appeared to be the key factor in determining success, rather than the scope or magnitude of the difference they made. Feedback from others contributed to the feelings of success.

‘The president really appreciated my work and effort’. (Glen)

However, most participants said that they did not regularly receive feedback, and that they measured success in terms of the effect they had on the lives of others.

INT: How do you know you’ve done a good job? How do you define successful volunteering?

Scott: When they start singing.

Bruce defined success as having influence and effecting the decisions made by the boards and committees on which he volunteered, regardless of the popularity of his opinions.

‘They hate you but they want you back again. In some situations you know you’ve upset the applecart but you get the outcome you want’.

Success, it emerged, was based on a personal judgement consistent with the participants’ individual values and sense of achievement, and as Bruce illustrated, in some cases linked directly to the outcomes of their voluntary work.

Discussion

The aim of this study was to explore the experiences of individuals with CCN who volunteer. The results indicate that control is the main factor determining the nature and outcomes of their experiences. Control impacts on every aspect of volunteering including (a) the reasons why individuals with CCN volunteer and their ability to act on their motivations, (b) the benefits they receive, and (c) the barriers they face. The effect of control on each of these aspects of volunteering, and strategies for promoting control, are discussed below.

Motivations

The participants were motivated to volunteer in order to make a difference in their own lives and to the lives of others. These are the same motivations reported in previous studies involving adults with lifelong disability [5] and without [8]. However, the specific factors underlying these motivations were unique to each participant, based on his or her individual goals and life experiences. Sue, for example, was emphatic in expressing her desire to move beyond the activities available through her day service and to ‘...get out into the world and do something’. For Sue, as for many participants, volunteering represented a bridge to greater community participation and to further meaningful societal roles.

Having CCN did not appear to reduce the participants' desire to volunteer. In fact, for many participants, having CCN was their key motivation to volunteer because they were determined to educate others and to address those with disabling attitudes. Consequently, these participants volunteered in disability organisations, presenting disability awareness training to school students and members of the public. Simpson [7] suggested that although individuals with disability often volunteer in disability organisations due to an element of self interest, they also engage in a wide variety of other volunteering roles. The results of the present study support this assertion, as evidenced by participants also volunteering in a range of other roles including broadcasting on community radio and volunteering in the performing arts and in political organisations.

Having CCN did, however, make it hard for many of the participants to act on their motivations to volunteer and to take control of the situation. Those who had less effective communication skills found it difficult to seek voluntary work independently and were more reliant on staff to present them with opportunities. In this way, having CCN reduced the amount of control they had over the process of seeking and engaging in voluntary work. Therefore, strategies to promote and support volunteering amongst individuals with CCN must include the development and support of effective communication. This will help to ensure that individuals with CCN can access the many benefits that come with volunteering.

Benefits of volunteering

Volunteering resulted in a range of benefits for the participants. Consistent with those reported in previous studies, these benefits included (a) the development of knowledge and skills [5, 10, 11], (b) increased preparedness for paid work [7], (c) increased self-esteem and

confidence [7, 10, 11], (d) expansion of their social networks [5, 10, 11], and (e) the personal satisfaction and enjoyment that came through helping others and themselves [10, 11]. A unique finding in the present study was that several participants indicated that through volunteering they had enhanced their communication skills. This suggests that for some adults with CCN, volunteering may provide an ideal context in which they can practise and develop their communication skills which may in turn lead to greater participation in other meaningful societal roles such as post school education and paid work. Volunteering may also provide an ideal context for adolescents with CCN who want to develop their communication skills ahead of finishing school.

The participants' reported that their volunteering also resulted in benefits for others through bringing happiness, educating and changing attitudes, and advocating for the rights of other individuals with disability. In addition, they reported that the organisations in which they worked benefited from their unique skills and life experiences. These outcomes further demonstrate that adults with CCN can be, and are already, providers of valuable community service [2, 7]. In addition, they underline the value of initiatives taken by organisations, such as the International Society for Augmentative and Alternative Communication, to recruit individuals with CCN to leadership positions [9]. However, despite these benefits, the findings also indicate that adults with CCN face a range of barriers in their attempts to volunteer which limit their control over their volunteering experiences.

Barriers to volunteering

The participants faced a range of barriers in their attempts to volunteer, consistent with the results of previous studies. These included problems with access [6, 11, 15], transport [5, 11, 23], and negative and disabling attitudes [5, 6, 11, 15]. However, for the participants in the

present study, the greatest barrier was communication. Having CCN not only made it difficult for the participants to interact with fellow volunteers and members of the public, it also amplified all of the other barriers they faced and gave them less control over their volunteering experiences. Participants who had less effective communication skills had difficulty (a) expressing their motivations to volunteer, (b) finding and apply for volunteering positions, (c) organising appropriate support, and (d) advocating for themselves when faced with participation barriers. These results support Balandin et al.'s [15] findings that communication can be a barrier to individuals with lifelong disability volunteering, and indicate that for individuals with CCN, communication is in fact the single most important barrier. Therefore, these findings also demonstrate the need for adults with CCN to have access to appropriate communication support, including effective AAC systems, in order to address the participation barriers associated with volunteering.

Strategies for supporting volunteers with CCN

The use of AAC was the strategy most commonly used by participants in an effort to address their communication needs. Eighteen of the 24 participants used AAC as their primary communication mode, and several participants commented that volunteering would have been extremely difficult, if not impossible, without it. However, many participants reported that they found it hard to gain access to the AAC systems and support they needed due to issues such as funding and a lack of training resources. These issues have been highlighted in the AAC literature [e.g., 24, 25] and indicate that problems accessing effective AAC systems are not unique to the context of volunteering, but instead reflect the systemic barriers that many adults with CCN face in accessing the AAC systems they require. Therefore, a broad approach is required to addressing the communication needs of adults with CCN is required to ensure they

have access to effective communication across a range of meaningful societal roles [26], including volunteering. An equally holistic approach is needed when providing the support each individual requires to volunteer successfully.

The participants emphasised their need for access to appropriate formal and informal support when volunteering. Informal support, provided by family and friends, helped participants deal with stressful situations when volunteering, whereas formal support made seeking and carrying out voluntary work possible for most participants. Those who lacked adequate formal support, due to inadequate funding or organisational policies dictating the distribution of support time found it hard, and in some cases impossible, to volunteer. Policies that limit funding and support have been identified as key barriers to individuals with CCN participating in society [27]. Therefore, commitment from organisations and governments is needed to ensure that individuals with CCN have the resources and support necessary for them to achieve their volunteering goals. In addition, it is important to ensure that the support provided is appropriate.

The participants highlighted the influence that support staff had on their experiences of volunteering. Staff who (a) listened, (b) valued them and their volunteering work, and (c) tailored their approach to meet their individual needs ensured that the participants remained in control of the decisions made regarding their volunteering, even though support was required. Given that staff behaviours are known to influence the participation levels and empowerment of adults with lifelong disabilities [28], it is important that adults with CCN have control over the nature of their relationship with support staff when volunteering. However, managing the relationship, including negotiating roles and providing feedback, may be difficult for some adults with CCN, as demonstrated when negotiating attendant care [26, 29]. It is imperative, therefore,

that adults with CCN have access to effective communication systems in order to support them to seek, access, and direct support to meet their individual needs.

Implications

The findings of this study highlight the need for adults with CCN to have control over their volunteering experiences. In order to enhance control, they must have access to effective communication systems and appropriate support. The participants in this study demonstrate that some adults with CCN want to volunteer [5, 6] and that organisations should target them as a ready and willing workforce [7]. Recruiting adults with CCN into volunteering positions has the potential to correct imbalances in community participation, while organisations benefit from the skills, knowledge, and experience they have to offer [2, 11]. The contribution of volunteers with CCN needs to be acknowledged in order to balance the perception that they are only recipients of community service [7] and the barriers to their participation should be identified and addressed [6]. The findings also highlight the complex nature of volunteering when a person has CCN. The unique barriers resulting from communication difficulties are in addition to those faced by adults with lifelong disability who do not have CCN. Therefore, it may be beneficial to develop and evaluate training materials and guidelines, based on these findings, which staff can use to better support those who want to volunteer.

Limitations of the study

The theory presented in this study, that control is the single most important factor determining the outcomes of volunteering for adults with CCN, is a substantive rather than formal theory [19]. That is, the theory is only intended to account for the experiences of the participants in the present study, not the experiences of all adults with CCN who volunteer. Therefore, care must be taken in interpreting the findings and applying the recommendations. In

addition, the aim of this study was to explore the participants' experiences of volunteering based on their own perceptions, not the perceptions of others. It is possible that support staff, volunteer coordinators, and fellow volunteers may have had different views of the participants' experiences and outcomes of their voluntary work.

Future research directions

Further research is needed in order to examine the experiences and perceptions of staff members and fellow volunteers who support and work alongside adults with CCN who volunteer. These studies may shed additional light on the experiences of volunteers who have CCN and further inform the development of strategies to support them.

Conclusion

Many adults with CCN are motivated to volunteer alongside their peers without disability in order to make a difference to their own lives and the lives of others. However, they require effective communication systems and appropriate support in order to address the participation barriers they face in their attempts to volunteer. With appropriate support, individuals with CCN can have control over their volunteering experiences and achieve far reaching benefits and rewards for themselves, others, and their communities.

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Appendix 1

Semi-Structured Interview Guide

Volunteering Questions

- Can you tell me about your experiences as a volunteer?
- Why did you decide to volunteer?
- Why do you think other people decide to volunteer?
- How did you define success as a volunteer?
- How does using AAC impact on the success of volunteering?
- Are there things that make volunteering difficult for people with physical disability?
- What advice would you give to other people who use AAC who want to volunteer?
- What advice would you give to organisations to encourage them to use people with physical disability who use AAC as volunteers?
- What do you see as the future for volunteering amongst people who use AAC?

Demographic Questions

- What is your date of birth?
- Can you describe your AAC system for me?
- How long have you used this system?
- Is this the system you use/d when you volunteer/ed?
- Where did you go to school?
- Are you still continuing your education?
- Are you employed or have you worked in the past?
- What kind of work do you do?

- How often do you work?

Table 1

Participant Demographics

Pseudonym	Age	Mobility	AAC	Volunteering Role	Currently Volunteering ³	Education ⁴	Current Employment	Accommodation
Peter	40-50	Power wheelchair	SGD ¹	Community Radio Youth group leader	No	Secondary	Unemployed	Group home
Craig	50-60	Power wheelchair	SGD	Committee member	Yes	Tertiary	Supported employment	Family home
Anne	30-40	Wheelchair	SGD	Fund raising	No	Tertiary	Unemployed	Group home
Lisa	40-50	Wheelchair	Board ²	Preschool	No	Secondary	Unemployed	Group home
Luke	30-40	Power wheelchair	SGD	Trainer	No	Secondary	Unemployed	Group home
Lee	50-60	Wheelchair	Board	Preschool	No	Secondary	Unemployed	Group Home
Sue	30-40	Powered	SGD	Trainer	Yes	Tertiary	Unemployed	Group home

		wheelchair						
Jack	40-50	Power wheelchair	Board	Hospital	Yes	Secondary	Unemployed	Group home
Emily	20-30	Power wheelchair	SGD	Mentor	Yes	Tertiary	Unemployed	Group home
Scott	60-70	Power wheelchair	SGD	Musician	Yes	-----	Retired	Group home
Jeff	20-30	Power wheelchair	SGD	Hospital	No	Tertiary	Unemployed	Own home
Gary	40-50	Wheelchair	SGD	Church	No	Tertiary	Unemployed	Group home
Laura	30-40	Wheelchair	SGD	Mentor	Yes	Tertiary	Unemployed	Family home
Eric	50-60	Power wheelchair	Board + SGD	Trainer	Yes	Tertiary	Casual employment	Own home
Tina	30-40	Power wheelchair	SGD	Artist	No	Tertiary	Casual employment	Family home

Bruce	30-40	Power wheelchair	SGD	Committee member	Yes	Tertiary	Casual employment	Own home
Dawn	40-50	Independently mobile	SGD	Committee member	Yes	Tertiary	Employed	Own home
Carl	50-60	Power wheelchair	SGD	Committee member	Yes	Secondary	Retired	Own home
Beth	40-50	Power wheelchair	SGD	Committee member	Yes	Tertiary	Employed	Own home
Glen	50-60	Power wheelchair	SGD	Committee member	Yes	Tertiary	Unemployed	Group Home
Cathy	50-60	Independently mobile	SGD	Committee member	Yes	Secondary	Casual employment	Family home
Tim	50-60	Power wheelchair	SGD	Trainer	No	Secondary	Casual employment	Own home
Amy	30-40	Power wheelchair	Board	Trainer	No	Secondary	Unemployed	Family home

Emma	50-60	Power wheelchair	SGD	Trainer	Yes	Tertiary	Unemployed	Own Home
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¹ Communication board.

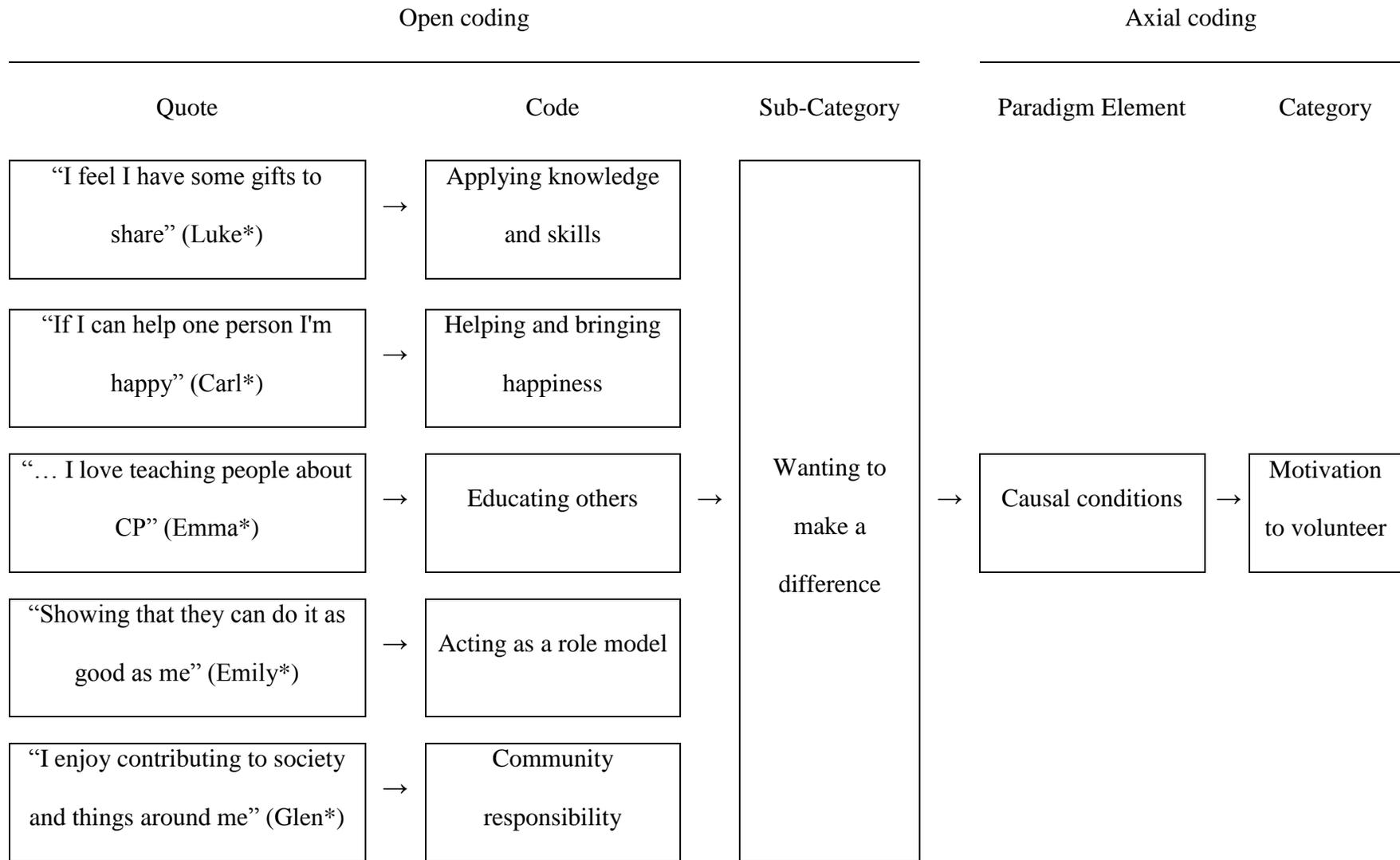
² SGD = Speech generating device.

³ Includes those participants who engage in intermittent volunteering roles and who expect to volunteer again within six months.

⁴ The term 'tertiary education' refers to completion of one or more subjects or a full course or degree at the tertiary level.

Figure 1

Example of open and axial coding leading to the development of the category of 'motivation to volunteer.'



* Pseudonym

Figure 2

Theoretical model accounting for the experiences of volunteers with complex communication needs.

