

EVALUATION REPORT

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**Participant Led Training
Videos**

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ENQUIRIES
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Executive Summary

This evaluation has independently reviewed the process and outcomes of a novel project that set out to co-design, pilot, and document a process for working with NDIS participants to produce participant led training videos (PLV) that inform disability support workers about how the person with disability wants to be supported. The evaluation covered multiple perspectives and included quantitative and qualitative data from 14 participants: five primary participants (PP), five close other supporters (COS: two family members, three disability support workers) and four staff facilitators (SFF). Primary participants included four men and one woman. They all had acquired brain injuries (ABI) with resultant cognitive and communication impairments and very high support needs.

Results provide evidence of high levels of satisfaction with the process across all participants. Usefulness of the approach was also highly endorsed by participants in the three groups. Primary participants and their supporters recommended the process for others with an average rating exceeding 8 on a 10-point scale. Experiential data revealed a person-centred experience for primary participants that was structured around sense of self through a process of ‘being me’ to ‘showing me.’

It wasn't just this video about, you know, this is what you do or that. I saw him in it, and him sitting there. ... I like the way that there was that, like I said, humanness captured about him. His personality shone through. Yeah I liked that. ... It's like you're meeting him. (COS of PP1)

Critical results revealed in the evaluation included the importance of people with disability having a voice and taking control in directing their lives, personal growth through participation and engagement, and feeling validated through the experience.

The production and use of PLV training resources has much potential to improve the delivery of support and maximise support outcomes for people with disability. Indeed the results of this evaluation indicate it provides a feasible approach that can enable people with cognitive and communication impairments to have choice and control, set their own goals and direct their supports. Thus, it delivers a methodology through which several principles of the National Disability Insurance Scheme can be operationalized for individual participants.

Introduction

This evaluation was commissioned as part of a larger project entitled 'participant led training videos' (PLV). The project undertook to co-design, pilot, evaluate and document a process for working with National Disability Insurance Scheme (NDIS) participants with cognitive and communication impairments to produce participant led training videos that inform disability support workers about how the person with disability wants to be supported.

In order to inform the project and its evaluation, we conducted a customized review of the English language academic and grey literature published from January 2006 to October 2017. The aim of the review was to identify and retrieve studies on production of participant led training videos that could inform support workers on how people with cognitive and communication impairments want to be supported. The literature search retrieved four key articles. While only one article (Davidson, 2015) outlined the co-creation of self-advocacy videos, Lorenz and Chilingirian (2011) described the use of photo-voice or photo-elicitation to better understand patient preferences, and Garcia-Iriarte et al. (2009) and Lakhani et al. (2017) both explored techniques for capacity development with persons with cognitive disability. Together these articles identified three key principles of relevance to the implementation of participant-led self-advocacy videos. These key principles included: 1) Capability or strengths focus; 2) Engagement strategies; and 3) Feedback process (see D'Cruz & Douglas, 2018).

While capacity building and seeking the views of people with cognitive disability is increasingly understood to be integral to best practice, the findings of our literature review indicated that there was little and limited research evidence to guide development and implementation of participant led support resources. Further, although technology has increased in availability and accessibility, the majority of research and intervention continues to use technology to educate or train people with disability, rather than enabling them to use technology to have a voice in directing their lives (Davidson, 2015). The key implementation principles identified through the literature review inform capacity building approaches that enable adults with acquired cognitive disability as self-advocates. These principles have relevance in the context of this participant-led training video project.

The results of the four published studies also demonstrate the ways in which these capacity building

approaches can positively impact participants. Davidson (2015) described the personal growth experienced through participation in the co-creation of videos as participants developed new skills, reflected upon their own capacity and felt validated by contributing to society. This finding is consistent with a recent scoping review of personal narrative approaches in brain injury rehabilitation that identified positive personal growth through feeling heard and validated through the experience of personal story sharing (D’Cruz, Douglas & Serry, 2017).

Garcia-Iriarte et al. (2009) found that use of a participatory action research (PAR) approach enabled participants to move beyond participation guided by facilitators to taking control of the advocacy group. They argued that shifting control away from the facilitator to the participant is key to capacity building or growth, suggesting further attention to the ways in which people are supported to exercise control. This growth was also reported by Lorenz and Chilingirian (2011) as participants in their study were observed to shift from participant to ‘co-expert’ when given the opportunity to share their personal lived experience. While Davidson (2015) recognised that for some participants, seeing oneself on video can be challenging, this was ameliorated with opportunities for participants to privately view videos before sharing, editing videos until they were satisfied with the end product and in some instances, sharing with others and receiving positive feedback.

Lorenz and Chilingirian (2011) noted that not only did participants experience personal growth through sharing their lived experiences of disability through photography, participants also developed a stronger therapeutic connection with their healthcare provider, were better engaged in rehabilitation, accepted more responsibility and showed a better understanding of the rationale for all clinical decisions. Consistent with research into person-centred approaches to goal setting and rehabilitation, patient and healthcare provider expectations and goals were better aligned. In summary, the findings of the literature search, while limited, indicate measurable value in adopting a participant-led training video approach to the development of training resources to inform disability support workers about how the people with whom they work want to be supported.

Aim

With this limited evidence base as background, our evaluation of the project was conducted to gain an understanding of the experience and to measure satisfaction with the process from the perspective of all those involved: primary participants with cognitive and communication impairments, close other participants who

supported primary participants through the process, and staff who facilitated the video production process. We anticipated that the evaluation findings would inform further development and fine tuning of the approach to underpin its application more broadly in the context of support provision for people with disability including those with cognitive and communication disability.

Method

PARTICIPANTS

The project involved 14 participants: five primary participants, five close other supporters (two family members, three disability support workers) and four staff facilitators. Primary participants included four men and one woman. They all had acquired brain injuries (ABI) with resultant cognitive and communication impairments and very high support needs; verbal communication was a substantial challenge for four of the five primary participants. One primary participant lived in a residential aged care (RAC) facility, two in shared supported accommodation (SSA), and two at home with family members. Close other supporters were either family members or disability support workers who had a longstanding relationship with the primary participants. Facilitators were employees of the Summer Foundation with substantial practice experience in either clinical or person-centred digital story production environments; one staff facilitator covered the management role for the project.

DESIGN

A mixed method research (MMR) design (Tashakkori, 2009; Teddlie & Tashakkori, 2010) employing elements of qualitative and quantitative paradigms was used to evaluate the experience of and measure satisfaction with the PLV project from 3 perspectives:

- Primary participants (PP) – people with complex support needs who make a video to meet their nominated goals/needs concerning the support they receive in their everyday lives.

- Close other supporters (COS) – people (e.g., family members, allied health professionals, support workers, house coordinators) who are actively involved with the primary participant in the process of producing the video.
- Facilitators (SFFs)– Summer Foundation staff members who facilitate the production process.

A constructivist qualitative approach was applied to the exploration of the experience of participating in the project. Given the intent of the qualitative arm of the evaluation was to develop understanding grounded in the experiences of participants, the PLV process was explored within a constructivist Grounded Theory framework (Charmaz, 2006, 2009). Grounded theory is well suited to social inquiry when there is a relative lack of established information about the phenomenon of interest and researchers believe they can learn from participants how to better understand that phenomenon (Bluff, 2005; Browne, 2004). A quantitative approach was used to index primary participants knowledge of their support needs and to rate the satisfaction and enjoyment of primary participants and their close other supporters with each component of the video production process. As recommended for MMR (Teddlie & Tashakkori, 2010), the evaluation components were designed and implemented to address related aspects of the same question with the intention of integrating the results emerging from both approaches (see figure 1).

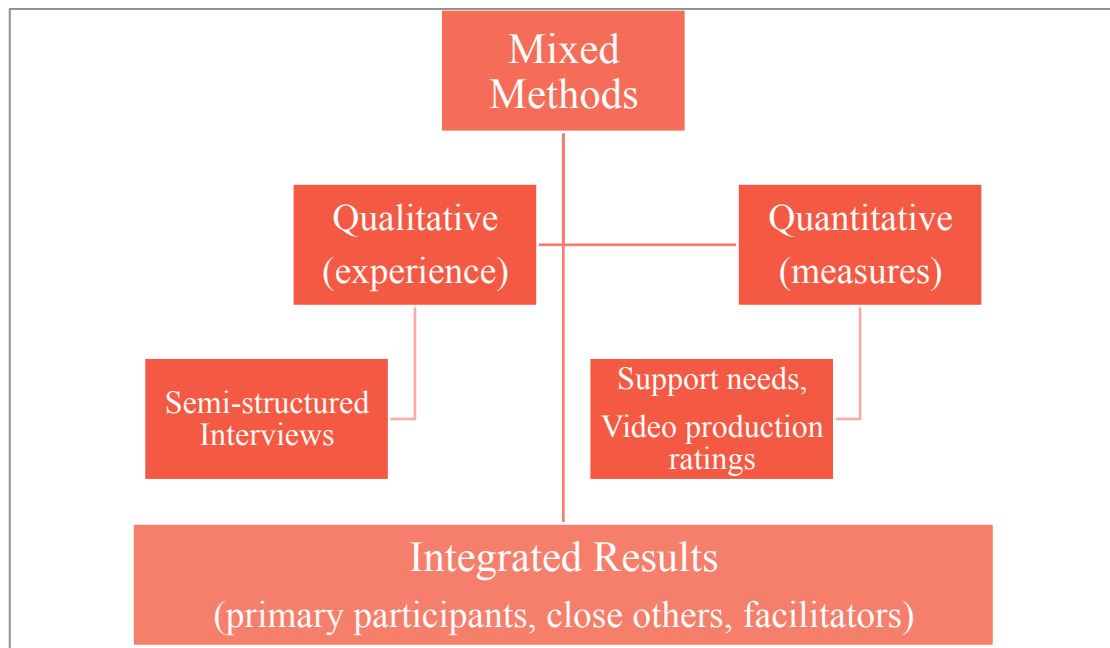


Figure 1. Evaluation design using mixed methods

PROCEDURE

Primary participants and close other supporters were interviewed and completed questionnaires in the home environment. Interviews were conducted following completion of the video resources and after the participants had viewed their finished product. Facilitators were interviewed in the Summer Foundation offices.

Rating Scales

Customised rating scales were developed for the project to index four constructs from the perspective of primary participants and close other supporters: i) the primary participants' knowledge of their support needs (SN) and satisfaction with the support they received in the past); ii) satisfaction and enjoyment of the PLV process across each of its five component parts (goal setting and video planning, scripting and storyboarding, filming the video, watching the video and choosing which parts to share publicly, the finished video); iii) likelihood of recommendation of the approach to other people like themselves; and iv) overall usefulness of the approach. A 5-point response format (1 very low to 5 very high) was used for all these scales with the exception of the recommendation scale that used a rating from 0 (not at all) to 10 (very likely). Facilitators rated usefulness of the clinical approach and its contribution to the delivery of support in the sector on a 5-point scale (1 very low to 5 very high).

Interview Format

The semi-structured interview format was broad based and allowed the participants to reflect on their experience across each component of the video production process including strengths and weaknesses, their feelings about the final product and recommendations for the further development of the approach. Interviews were conducted by an allied health professional with many years experience working clinically and in research with people with cognitive and communication impairment.

ANALYSIS

Quantitative

Descriptive statistics were calculated using scores on each item of the scales used to rate support needs, satisfaction and enjoyment (with the video production process), personal recommendation (to others in a similar position) and usefulness of the approach.

Qualitative

Grounded theory focuses on extracting meanings that people give to actions and events. Analysis moved through a process of data-driven open and focussed coding, identification of emergent categories and exploration of relations between these categories using the method of constant comparison. Initially, verbatim transcripts were examined and textual excerpts were coded to reflect the meaning of the words recorded. As the data from each successive interview were compared and contrasted in an iterative process, codes became increasingly focused until clear categories and core concepts emerged. Categories were reviewed against the original transcripts to ensure that they maintained the voice of the participants and were anchored in their experience. Finally, to show the reader that the analysis is fully grounded in the participants' accounts of themselves, illustrative quotes from the interviews are presented throughout the text. In order to protect the identity of participants, their names are not used and each quote is designated with their participant group and a number (e.g., PP1 = primary participant 1; COS of PP1 = close other supporter of primary participant 1).

Results

KNOWLEDGE OF SUPPORT NEEDS

Primary participants rated their knowledge of their ongoing support needs (SN1) at a medium level and their knowledge of how to make plans for themselves (SN2), how they liked to be supported (SN3) and how workers and professionals need to support them to meet their needs (SN4) at a high level. In contrast, they rated their satisfaction with the support they had received in the past (SN5) at a low level (see figure 2).

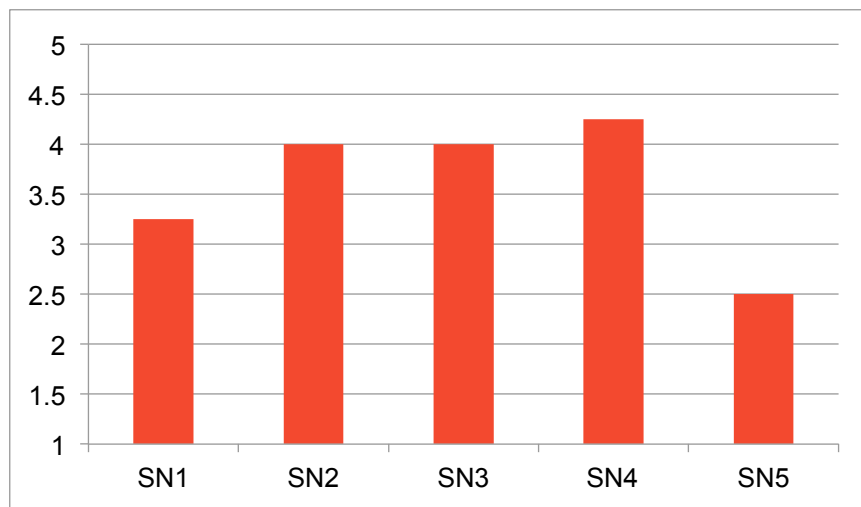


Figure 2. Primary participants self ratings of knowledge of their support needs

PARTICIPANT LED VIDEO EXPERIENCE

Analysis of the interview transcripts revealed that primary participants' experience of leading the development of their own support videos emerged as a personal process of development beginning with the internalized structure of self, "being me," to an authentic externalized representation of self, "showing me." Five themes characterised the experiences that underpinned the overall process of leading the production of their own support focussed video: *knowing me and my support needs*; *sharing what's important to me*; *having a voice*; *working hard*; and *reviewing and sharing my achievement*. While these thematic categories overlapped and coexisted with each other, a temporal sense of an empowering process of moving from *being me* (the person I am) to *showing me*, beginning with *knowing me and my needs* and moving to a point of *sharing my achievement* (the video) was also conveyed across participants' construction of the experience. The overall process is illustrated in figure 3 with the inner themes acting as feed forward and feedback pathways between the starting and end point of the process.



Figure 3. Participant led video experience: *From being me to showing me*

Sense of self (who I am) acted as the structure around which primary participants had processed their experiences and how the close other supporters had gauged the quality of the experience for the primary participants. Recognition of self and identity framed the importance of *knowing me and my support needs* in the context of providing support.

When they did say that they wanted to make a video and training film I said yep, no problem because over the years we're going to have new carers coming in. So they need to know what his needs are and everything like that, like who he is. (COS of PP3)

It's more about him as a person and what he needs – what makes him a human being; what things can make him feel better – yeah his personality and who he is as a person. And that's what he likes. (COS of PP1)

The central influence of self continued through the next theme; *sharing what's important to me* and was seen to underpin an effective working relationship between primary participants and those who support them.

He (PP1) knows what he wants. A lot of his frustration is around not being understood or having his needs met. So he's got a few things that are very important to him and he chose those goals in his video. And if we can get that right and he feels that he's being understood, it makes his life a lot easier ... it just makes his life a whole different thing. So really those three things is what he chose, they're the things that are important to him. And if people know what he's asking for, he'll get a sense that they know him, and that's how he forms relationships with people too. (COS of PP1)

It was easy because I was understood.... (it was about) what I need ... (the things) that are important. (PP4)

The video production opportunity brought with it the satisfying experience of not only being acknowledged as an individual, but *having a voice* and exercising choice in their own lives for the primary participants. Participants' supporters saw this consequence of the experience as particularly positive.

It was good because we were giving them feedback, so everything was sort of right and we were going through it together. He had the choice to say yes or no and you know, it was really, really good. (COS of PP3)

And he was asked again to make sure they got it – you know they were getting his answer and not sort of feeding him the answer ... and it's coming from him ... and he spoke, he stood up and he spoke, and he said what he needed to say, he was actually assertive. (COS of PP1)

My words were important ... in words that I wanted to develop the script. (PP4)

Primary participants and close other supporters reflected on *working hard* and feeling challenged through the process. This response was particularly the case for primary participants during the filming component which drew heavily on their cognitive, emotional and physical capacity.

Nervous, I was feeling very rushed ... because I had to talk a lot and to remember to say the script.
(PP4)

It was a bit sort of intense. I think that was probably the day that he told them yeah, "That's it. I've had enough. You're not going to get any more out of me. I've given you all I can." ... It was probably a bit long. (COS of PP1)

Yeah well he does get a bit tired during the day – he has a couple of naps. ... It was particularly hard for him, it was tiring. ... It was a bit cramped with the lighting. ... And that's (during filming) when you could tell he was getting a bit fatigued. (COS2 of PP3)

Working hard through filming culminated in a sense of achievement and a positive sense of emotional release and celebration was reflected in *reviewing and sharing my achievement* across participants and their close other supporters.

It was good and he was laughing at it and pointing to it. ... It was outstanding to see him do it. I mean it was - he done really well. I think he was proud of himself too. ... I was pretty rapt because you don't see him talk like that. I mean he says two or three words at a time but not like that. And it was – just sort of blew you away. (COS2 of PP3)

When they put it on it was really sort of – yeah we both couldn't take our eyes off there and then. Every time we're sort of looking at each other and laughing at different things and yeah I shed a tear. I don't know. I became quite emotional and I just thought – it just captured him, and I thought yeah, there he is. So it was good, I like it. ... It's like you're meeting him. (COS of PP1)

Oh yeah he was stoked, you know. His eyes were lit up, and he didn't take his eyes off it. (COS of PP1).

For some participants, reviewing their achievement also triggered recognition of areas for improvement in their individual experiences and a sense of wanting more.

It was more just the early on in the process (goal setting and planning), the confusion about, well, what do they want from me? ... The actual cameraman, sound person, lighting person were really, really good. I think it was very effective in the end. (PP5)

Started well (goal setting and planning)... it went down, the filming (fast and too short) and the expectations of me (too high on the day). Interviewer clarification: You couldn't fit everything in to the video that you wanted? Yep. (PP4)

Finally, the opportunity to share the video gave participants a means of going beyond support training to revealing self, *showing me*.

It wasn't just this video about, you know, this is what you do or that. I saw him in it, and him sitting there. ... I like the way that there was that, like I said, humanness captured about him. His personality shone through. Yeah I liked that. ... It's like you're meeting him. (COS of PP1)

But I think you know, I think he just yeah, you know, but I just think he felt that there was a lot in there that really did represent him and what he wanted to say. ... He really loves it when people get to know him and value him and have meaningful interaction. And I think that – after this – not what we originally thought but suddenly you know I thought it was. (COS1 of PP2)

SATISFACTION AND ENJOYMENT

Mean satisfaction ratings for primary participants and close other supporters across each component of the video production process are shown in figure 4; enjoyment ratings are shown in figure 5. Average satisfaction ratings were all at the high end of the scale (> 3.5) and close other supporters ratings tended to be a little higher than those of the primary participants. Mean satisfaction with the video product was high (4.0) to very high (5.0) across both primary participants and close other supporters. Across components of the process, primary participants gave the filming experience the lowest satisfaction rating. Enjoyment ratings tended to follow the same pattern across components and participant groups and enjoyment of the video product was particularly high (primary participants 4.67; close other supporters 5.0).

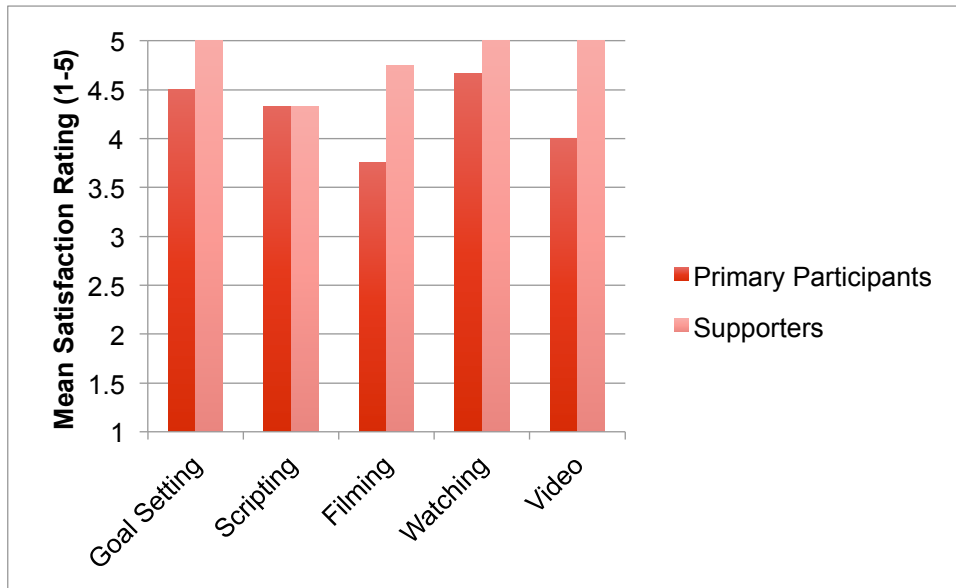


Figure 4. Mean satisfaction ratings across components of video production

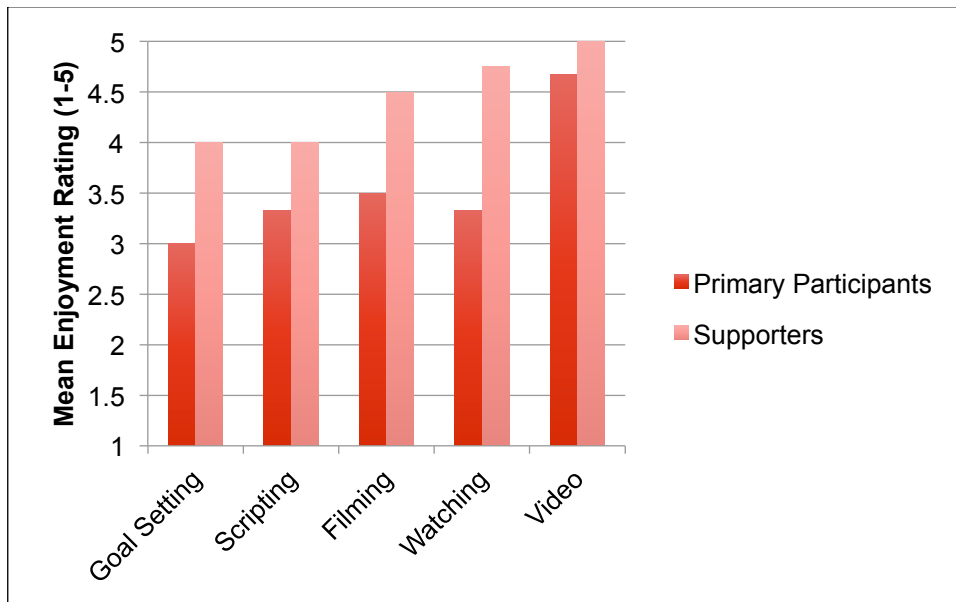


Figure 5. Mean enjoyment ratings across components of video production

RECOMMENDATION TO OTHERS AND USEFULNESS OF APPROACH

When asked to rate how likely participants were to recommend this approach for other people in similar circumstances responses were extremely positive (see figure 6). Mean ratings of usefulness of approach were also very high across the 3 groups of participants (see figure 7).

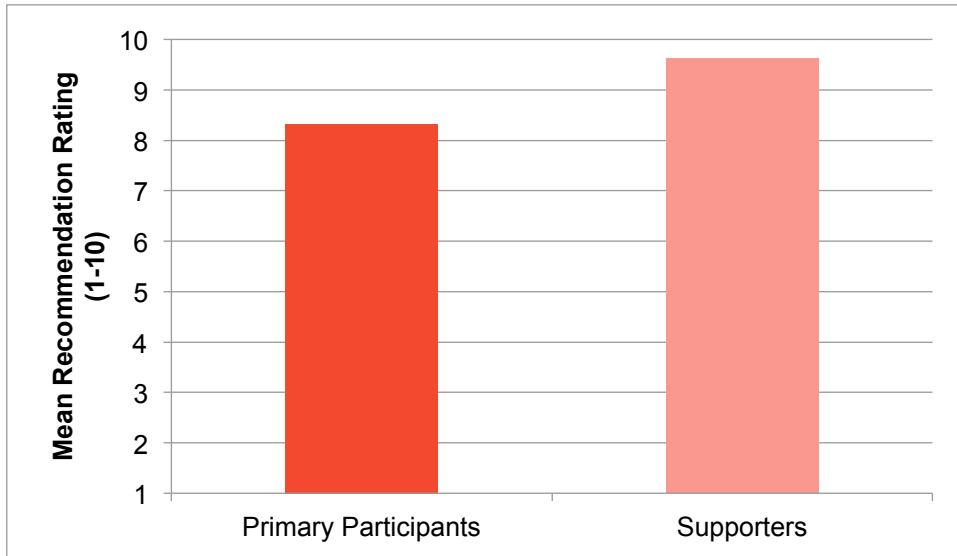


Figure 6. Mean recommendation ratings

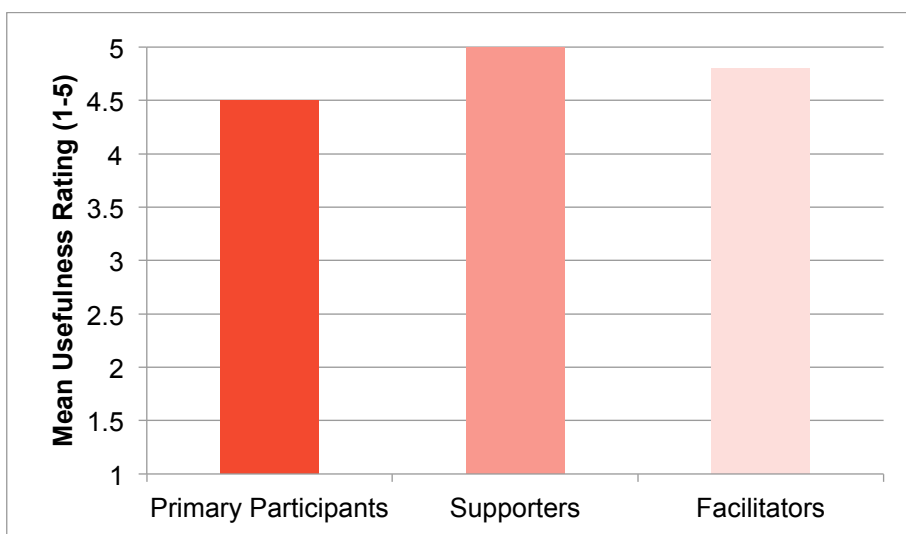


Figure 7. Mean usefulness of approach ratings

Along with their quantitative ratings, participants contributed a rich commentary about usefulness.

Useful – yeah I think it would be for new staff coming in and staff that come and fill shifts that are vacant and we're short on time, because it's not always time. And it just gives the – they can share with him. So it's that kind of going in to his flat with him and watching something about him. They kind of feel like – it's almost working with him for a few shifts and getting to know him. And you wouldn't really get to know him that well because if you're new you're sort of concentrating on other things, like practical things. (COS of PP1)

See sometimes you have carers in, you might have them in for a year, year and a half, and then all of a sudden they have to go. It will be good especially in the next couple of weeks, we've got another carer coming in and we've got one starting on Friday too. So it'll be good to let them watch the video and see how they go with PP3. (COS of PP3)

Participants also made constructive recommendations about the PLV process. These recommendations focused primarily around having more time available for the overall process and particularly during the scripting and filming component. One participant felt the filming process in his home with new people not previously known was somewhat challenging to personal privacy and recommended more preparation for this component, if a filming crew is being used. Both primary participants and close other supporters recommended production of additional videos to cover a range of personal support scenarios.

LEARNING FROM THE FACILITATION PROCESS

The themes of knowing the person, sharing what's important to them through their own voice and the positive sense of achievement and emotional release that emerged from the experience of the primary participants' and their close other supporters were also clearly evident in the facilitators' interviews.

Knowing me and my support needs

I read the storyboarding before I saw each video, and I cried through every single storyboarding because it really came through that the person was talking, directing their own care, and I didn't realise how much people don't do that. (SFF1)

It was just so powerful to be able to include people in designing something to empower themselves. It was just a fantastic process. And to know that all the people that we invited to participate really felt that at the end of it, and felt so – yeah like one of the participants had said to me – actually most of them said, “I can make a video to do that?” “Wow!” Like its just that “I can do that?” and then the sense of control that you could see that they have. (SSF2)

Sharing what's important to me

And the fact that you can – like I can watch PP3's video, and I'm a speechie, obvious, you know, in rehab, but I can watch it and I feel much more confident to go and see him, that I'd know, you know, I could talk about music, I could look at, like just by watching the 10 minutes. And PP5's video is about hydrotherapy – I was thinking I could take him to hydrotherapy. Like, I would confidently be able to do that. I think that's incredible. (SFF1)

And you could see there was a big gap in how his support was delivered because his video was really about how he wants his support workers to communicate with him – what he wants them to understand about the communication process. And to kind of bridge that gap between people having no idea about how to communicate with him and being reluctant to try because they didn't know how to get it right – to get to the point where the trying is the important thing. (SFF3)

Having a voice

People perceived the videos as having a lot of value and a lot of purpose and application for them - and they were definitely engaged. (SFF3)

Then the fact that it's been spoken from the person's perspective, even when the support worker does it, it's still the person, you know the person's agreed to it. ... It's got to stay participant led it's their video. (SFF1)

Well it's one of the most wonderful things about the project, is to be able to empower people. ... When people have really severe cognitive issues or communication issues and the support person is there, whether it's a family member or a support worker, the willingness of that person to actually let the person really set their own priorities was really – that was really evident. (SFF2)

Reviewing and sharing my achievement

And then the videos, like name (PP3), I've met twice. I've never heard him speak, you know I've heard him say, "yep, nup" lots of gesturing and then to see that video still makes me emotional thinking about it. (SFF1).

Yeah, once again it was a really emotional experience, because he (PP2) struggles a lot with fatigue. And by the time I got everything set up he was going off to sleep and you could just see the effort he went to to stay awake. And as the video went on, it wasn't a problem it wasn't a problem for him to stay awake. Like he was so engaged in watching it, or listening. Probably more listening and you could see him really channelling his energy to really connect. ... And he was able to communicate very clearly that the video had achieved what he wanted it to achieve. And that he was happy for us to share it... and he was proud of it. (SFF3).

It was amazing, because it was – it was both amazing to watch COS of PP3 (brother) because I think he had – yeah, when he watched it, he was just kind of like "Wow that's awesome." It was so powerful I think for him to see PP3 controlling his own care. And I think because COS of PP3 (brother) has been doing that for so long, for PP3 to be able to do that, have a way to access that control, was really powerful. So he was quite emotional. ... And to see him be so emotionally connected to it and so happy was beautiful. Because I think it's like a sense of relief almost as well. Like I got from him, like it was – yeah it's not all on my shoulders. (SFF2).

During their reflections of their experience, facilitators described modifications they made during the process, concerns they had about translation of the practice and recommendations for additional changes.

Discussion

This evaluation has independently reviewed the process and outcomes of a novel project that set out to co-design, pilot, and document a process for working with NDIS participants to produce participant led training videos that inform disability support workers about how the person with disability wants to be supported. The evaluation covered multiple perspectives and included quantitative and qualitative data from primary

participants (PP) with substantial cognitive and communicative impairments, their close other supporters (COS), including family members and disability support workers, and professionals who facilitated the video production process.

Results provide evidence of high levels of satisfaction with the process across all participants. Usefulness of the approach was also highly endorsed by participants in the three groups and primary participants and their supporters recommended the process with an average rating exceeding 8 on a 10-point scale. Experiential data revealed a person-centred experience for primary participants that was structured around sense of self through a process of ‘being me’ to ‘showing me.’ The process of participating in the making of a participant led video was characterized through five phases: *knowing me and my support needs; sharing what’s important to me; having a voice; working hard; and reviewing and sharing my achievement*. This overall personal growth and empowerment process and the phases within it were also strongly evident in the experience related from the perspectives of close other supporters and professional facilitators.

These findings replicate and extend those in the sparse literature that has previously considered the value of adopting a participant-led approach to the development of resources focusing on the needs of people with disability. Critical results revealed in this evaluation and the previous research include the importance of people with disability having a voice and taking control in directing their lives, personal growth through participation and engagement, and feeling validated through the experience (Davidson, 2015; Garcia-Iriarte et al., 2009; Lakhani et al., 2017; Lorenz & Chilingirian, 2011).

The evaluation reveals the impact of the PLV process at multiple levels. The process empowered the participants with disability, increased their confidence and autonomy and put them in the position of actively controlling their own support. It enabled these participants to experience a shift in their goal setting from a point where, after variable levels of discussion, goals and support are imposed on a passive recipient to the point of the expert who leads their own support. Indeed, it is confronting to consider this positive outcome more broadly. Theoretically all primary participants would already have goals as part of their NDIS plan and would have established “person centred” goals within the disability, health and rehabilitation service systems in which they had participated for many years. Yet these primary participants did not have documented goals easily at hand to refer to and expressed delight and relief at the opportunity to construct goals that resonated with them, used their own words, and truly reflected their values and their needs as they knew them. The importance of primary participants being given this opportunity to focus on and share goals that were important to them was

emphasised not only by the primary participants but also by their close other supporters and facilitators involved in the project. In fact, the facilitators noted an ongoing and pressing need to develop resources to support people with cognitive and communicative impairments to set goals.

Participant led video resources can also facilitate changes in support practice. Support workers can more readily see the person (not just the disability), the human individual. A move to a more “humanizing” perception has the demonstrated potential to reduce neglect and abuse in support and care situations (Ellis-Hill, 2018). PLV material also imparts readily applied practical knowledge about what to do and how to do it effectively and does so in the context of the expressed needs of the person with disability. Such participant-led resources are also likely to have a positive impact on system resources by reducing waste due to ineffective support that does not foster autonomy and independence. With positive changes in support practice, the burden that family members and significant others experience as a result of overseeing, training and retraining support workers is likely to reduce over time.

LIMITATIONS AND CHALLENGES

While this evaluation has brought to the fore many of the positive outcomes associated with the development of PLV resources, these outcomes need to be considered in the light of limitations of the research. Only a small number of people with disability and their supporters participated in this project. The people with disability had substantial cognitive and/or communicative impairments, very high support needs and relatively high levels of motivation. The facilitators directing the process all had highly relevant expertise and experience. Thus, the particular features of these two groups reinforce the need to evaluate the process and its scalability across groups reflecting wider ranging characteristics. In addition, the evaluation was conducted over a relatively short time period and does not reveal longer-term outcomes and implications of the approach. Systematic evaluation of outcomes beyond process and experience to frequency of video access and impact on goal achievement is also required.

Some of the challenges associated with wider and longer-term roll out of the approach were identified by the facilitators who participated in the current project. They expressed concerns about the skill levels of workers in the community being sufficiently skilled to create PLV resources. They also highlighted the pitfalls associated with maintaining the currency of resources, the functionality of display mechanisms, and appropriate

storage and access, as well as inappropriate use of the approach and uninformed or erroneous interpretation of resources.

As well as identifying challenges, facilitators also described potential solutions. For the most part, these solutions involved mechanisms to up-skill the disability workforce. They emphasised the need to develop, test and make available quality resources to guide the process and have commenced this task within the current project. Inclusion of education modules around use of the approach in degree level courses were also identified as potential solutions.

Conclusion

It's about the person, who they are, what's important to them, and that's just going to make everything else for them a lot easier and for the people they work with in the system. (COS PP1)

The production and use of PLV training resources has much potential to improve the delivery of support and maximise support outcomes for people with disability. Indeed the results of this evaluation indicate it provides a feasible approach that can enable people with cognitive and communication impairments to have choice and control, set their own goals and direct their supports. Thus, it delivers a methodology through which several principles of the National Disability Insurance Scheme can be operationalized for individual participants. Relevant NDIS principles that the PLV approach can directly contribute to include:

- enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports (section 3(1)(e));
- people with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation (section 4(6));
- people with disability should be supported in all their dealings and communications with the NDIA so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs (section 4(9)).

For people with disability, the opportunity to lead the development of effective training resources contributes to their conceptualisation of self, facilitates goal attainment and in turn promotes their wellbeing.

References

- Charmaz K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.
- Charmaz K. (2009). Shifting the grounds: Constructivist grounded theory methods. In: J. Morse, P. Noerager Stern, J. Corbin, B. Bowers, Charmaz K, Clarke A (Eds). *Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press (127–193).
- Davidson, A-L. (2015). A collaborative action research about making self-advocacy videos with people with intellectual disabilities. *Social Inclusion*, 3(6), 16-28.
- D’Cruz, K. & Douglas, J. (2018). Participant led training video: Literature review. Melbourne, Australia: La Trobe University.
- D’Cruz, K., Douglas, J. & Serry, T. (2017). Personal narrative approaches in rehabilitation following traumatic brain injury: A synthesis of qualitative research. *Neuropsychological Rehabilitation*, DOI: 10.1080/09602011.2017.1361844
- Ellis-Hill, C. (2018). *Working alongside people following brain injury: a ‘hands on’ exploration of human connection and sense of wellbeing*. Workshop presented at ASSBI 41st Annual Conference, Adelaide, Aus.
- Garcia-Iriarte, E., Kramer, J.C., Kramer, J.M., & Hammel, J. (2009). ‘Who did what?’: A participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities*, 22, 10-22.
- Lakhni, A., Watling, D.P., Zeeman, H., Wright, C.J., & Bishara, J. (2017). Nominal group technique for individuals with cognitive disability: A systematic review. *Disability and Rehabilitation*, DOI: 1080/09638288.2017.1325946.
- Lorenz, L.S. & Chilingerian, J.A. (2011). Using visual and narrative methods to achieve fair process in clinical care. *Journal of Visualized Experiments*, 48, e2342, doi:10.3791/2342.

Tashakkori, A. (2009). Are we there yet?: The state of the mixed methods community. *Journal of Mixed Methods Research*, 3, 287-291.

Teddlie, C. & Tashakkori, A. (Eds.) (2010). *SAGE Handbook of Mixed Methods in Social & Behavioral Research* (Second ed.). California: SAGE Publications Inc.