EMPIRICAL RESEARCH MIXED METHODS

Development and preliminary evaluation of a novel participant-led video intervention to train disability support workers

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Abstract

This paper describes the development and preliminary evaluation of a novel participant-led video (PLV) intervention to support people with disability (PWD) and cognitive and communication impairments to communicate their needs and preferences to their disability support workers. The PLV intervention was designed following a scoping literature review and workshop with PWD and close others. Subsequently, it was piloted with five primary participants with acquired brain injury and cognitive and communication impairments, five close other supporters and five facilitators. An independent mixed methods evaluation of the pilot was conducted with participants, close others and facilitators. All pilot evaluation participants reported high levels of satisfaction with the PLV intervention (mean ratings: primary participants 4.5/5.0; supporters 5.0/5.0; facilitators 4.8/5.0). When primary participants and their supporters were asked to rate how likely they were to recommend the PLV intervention, responses were extremely positive with the mean rating exceeding eight on a 10-point scale. Qualitative analysis of interview data revealed the PLV to be a person-centred experience for primary participants that was structured around sense of self and included having a voice and taking control in directing their lives, personal growth through participation 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 by enabling people with cognitive and communication impairments to have choice and control, set their own goals and direct their supports. Further research is required with a larger sample size and longitudinal evaluation of participant outcomes.

KEYWORDS
acquired brain injury, intervention evaluation, participant-led videos, people with disability, support workers

1 | INTRODUCTION

It is widely acknowledged in research literature that people with disability (PWD) benefit from support, not only to manage their daily living but to build their capacity to exercise choice and control and move towards self-direction (Bigby & Fyffe, 2009). This is especially relevant for people with high and complex care needs, such as those with cognitive and communication impairments (Bigby et al., 2017; Douglas et al., 2015).

In the Australian context, the National Disability Insurance Scheme (NDIS) implemented in 2013 (Parliament of Australia, 2013) provides individualised funding packages to Australians with disabilities to access supports. Paid disability support is primarily provided by disability support workers (DSWs). The role of the DSW is to provide necessary supports in line with the needs and preferences of the person with disability, ultimately supporting them to live an ordinary life and participate effectively in the community (Australia Government Department of Social Services, 2016; Australian Government Productivity Commission, 2017). Accordingly, a fundamental principle of the NDIS is to ensure that PWD have the right to exercise choice and control in directing their lives. Whilst this shift to a 'rights' focus for PWD is long overdue, many NDIS participants living with chronic disability do not have the cognitive or communication capacity 'in the moment' to exercise choice and control and to direct support services. Further, people with cognitive and communication impairments often have complex support needs and therefore require supports that are flexible and responsive to their changing abilities, needs and priorities over time. Thus, with a focus on personalised support for a diverse population comes greater demands on the disability workforce (Moskos & Isherwood, 2019).

In response to this challenge, the NDIS committed to spend $24.2 billion in 2019–2020 (National Disability Insurance Agency, 2020). Although this substantial increase in funding was expected to result in many DSWs with limited disability experience or education entering the labour force, limited resources were allocated for training (Cortis et al., 2017; Green & Mears, 2014; Moskos & Isherwood, 2019). Indeed, one of the key weaknesses of the NDIS is reliance on an unskilled workforce to support participants with cognitive and communication difficulties to obtain a good life, achieve their goals and increase their independence.

Whilst the experience and education of DSWs are important, quality of support is dependent on a multitude of factors (Topping et al., 2020). To provide individualised person-centred support, DSWs must learn the unique needs and preferences of the individual they are supporting (Fadyl et al., 2011; Gridley et al., 2014). However, with the high turnover rates and casualisation evident in the disability workforce, continuity of support can be compromised (Mavromaras et al., 2018; National Disability Services, 2018). Given this lack of continuity, DSWs have less time to get to know and build a productive working relationship with the individuals they are supporting (Bourke et al., 2019; Nilsson et al., 2016). Further, the high turnover of DSWs can be stressful and onerous for PWD who not only have to recruit new workers, but also train new DSWs to provide

What is known about this topic?

- The functioning of the National Disability Insurance Scheme in Australia has influenced a move away from training, as services have less funding for systems and infrastructure
- Improving the quality of support for people with cognitive and communication impairments is a complex process that requires an individualised approach.
- Tailoring support to the individual is key to quality support, but it can be difficult for people with cognitive and communication challenges to train support workers.

What this paper adds?

- Participant-led videos support people with cognitive and communication impairments to communicate their support preferences.
- The pilot evaluation revealed that people with disability, close others and facilitators report high levels of satisfaction with the participant-led video (PLV) intervention.
- People with disability experience PLVs as a person-centred intervention that they would recommend to others.

support in line with their needs (Gridley et al., 2014). Indeed, there are concerns that individualised funding schemes exacerbate inequities between disability types due to the complex administrative burden of ensuring the maintenance of an effective support team (Carey et al., 2017; Malbon et al., 2019). This inequality is likely to be the same with exercising choice and control over support arrangements. Specifically, for people with cognitive and communication impairments, training and leading their DSWs is likely to be considerably more difficult than for people with other types of disability. Thus, there is a need for mechanisms to help people with cognitive and communication impairments to lead their supports at minimal cost to themselves.

This study is the first of a series of studies within a larger project to develop an evidence-based intervention to improve the quality and consistency of disability support provided to people with cognitive and communication impairments. Improving the quality of support for people with cognitive and communication impairments is a complex process involving multiple stakeholders (e.g. PWD, family members and DSWs) and interacting components (e.g. skills, attributes and knowledge of the DSW, cognitive and communication capacity of the person with disability and external systemic factors) that requires an individualised and responsive approach. Video technology was chosen for this intervention, as it allows PWD to direct DSWs using their authentic voice, but with time to prepare and an option to update when needs and preferences change. As a multi-medium tool, we believe videos give richer insight into a person compared to written notes, enabling the support worker to see and hear

how the person interacts and wants to be supported. The research process underpinning the overall development of the Participant-Led Video (PLV) intervention was modelled on the four-phase approach for development and evaluation of complex interventions described by Craig et al. (2008). The four phases are (1) development, (2) feasibility and piloting, (3) evaluation and (4) implementation (see Figure 1). This project was completed by the partnering of two organisations. The advocacy organisation was successful in obtaining a grant to conduct the lived experience workshops and the pilot and the university was engaged to complete the scoping review and independent evaluation. Approval to conduct the independent evaluation was obtained from the university ethics committee. This paper presents the method and results of phases one and two.

2 | PHASE ONE: DEVELOPMENT

The aim of the development phase was to gather the existing evidence, both published literature and lived experience, relating to the production of the PLV intervention. Therefore, the development phase involved (a) a customised scoping review of the literature and (b) lived experience workshops with PWD and close others. Phase 1 was commenced in 2017 and concluded in 2018.

2.1 | Scoping review

Considering the scarcity of literature on the topic, scoping review methodology was chosen to systematically investigate and summarise existing research. This approach to reviewing the literature is typically adopted when searching topics with a broad research question, and no prior synthesis on the topic (Arksey & O'Malley, 2005; Levac et al., 2010). In undertaking this scoping review, the five-step framework developed by Arksey and O'Malley (2005) was followed. The

search was guided by the central research question: what video-based resources, tools and supports are effective in building the capacity of PWD to set goals, exercise choice and control and direct their care?

2.1.1 | Method

A customised search strategy was developed in consultation with a research librarian to identify relevant studies in academic and international grey literature from 2006 to 2017, with search terms guided by the research question. The search was conducted on five databases: CINAHL, MEDLINE, Embase, PsycINFO and Sociological Abstracts. As is consistent with scoping review methodology, preliminary searches were utilised to explore terms and guide refinement. For example, both 'goal-setting' and 'choice and control' retrieved a large proportion of irrelevant articles, so these terms were removed. It was also recognised that the concept of video technology was critical to the work of the PLV intervention, resulting in the addition of this concept and associated search terms to the search strategy. The final three concepts were: (1) population (intellectual disability, acquired disability, cognitive disability, communication disability, acquired brain injury (ABI), traumatic brain injury, mentally disabled) (2) capacity building approach to self-management (self-advocacy, capacity building, self-managing, self-coaching) and (3) video technology (video recording, narration, storytelling, podcast, blogging, website).

Keywords and database subject headings (where applicable) were searched for each concept (see Appendix S1 for an example). Following removal of duplicates, the search yielded 384 records. PRISMA guidelines were followed for the study selection process (Tricco et al., 2018). Inclusion criteria included: All literature, age 16 to 65 years, grey literature and years 2006–2017. Title/abstract screening of retrieved articles was conducted by the second author (KD) resulting in the exclusion of 371 articles based on eligibility criteria. An additional 10 articles were found through hand
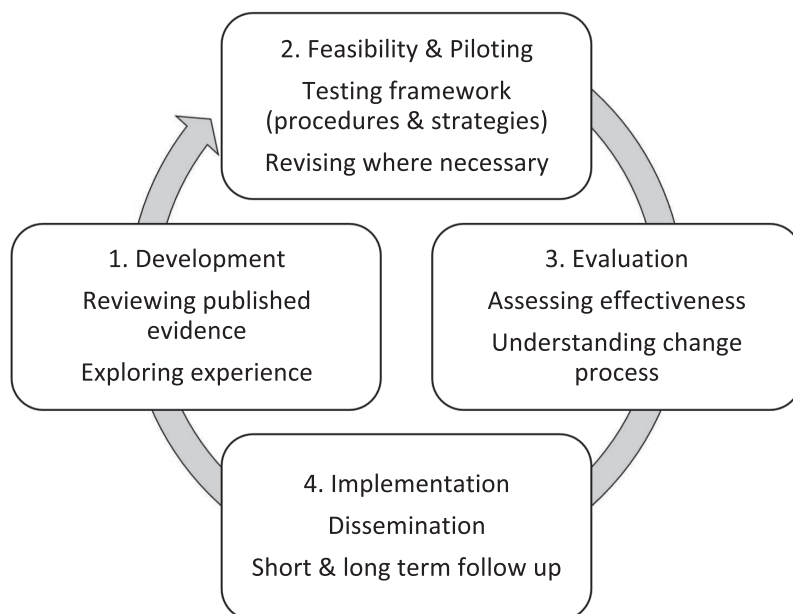

FIGURE 1 Process of development and evaluation: Modelled after Craig et al. (2008)

sort. In total, 23 full-text articles were double screened (KD & JD). Following eligibility screening and assessment of full-text articles, four relevant articles were reviewed. Grey literature was searched on Google, Google Scholar and PubMed using search terms utilised for the database searches.

2.1.2 | Results

The grey literature search revealed an enormous growth in patient care videos produced across healthcare systems internationally. For example, a Google search of 'patient experience videos' delivered nearly seven million sites that pertain to patient care and a large proportion of these demonstrated skills and interactions via video scenarios of patients with healthcare workers. Topics range from patient satisfaction, empathy, communication skills and handling specific situations (e.g. working with a distressed patient). The grey literature was evaluated for number of hits returned for specific search terms, and the first 250 results were reviewed for presence of participant-led content. However, most of these video resources, whilst inclusive of the patient perspective, were not participant (or patient) led with respect to the identified goal of the video resource being focussed on the individual. Given the lack of participant-led resources identified through the grey literature, a systematic search of the grey literature was not pursued.

Four relevant journal articles were identified through the peer-reviewed literature search (Davidson, 2015; Garcia-Iriarte et al., 2009; Lakhani et al., 2017; Lorenz & Chilingerian, 2011). These four articles were reviewed and data were extracted regarding population, study design and principles of intervention. Participants across the four articles included brain injury survivors (Lorenz & Chillingerian), adults with intellectual disability (Davidson; Garcia-Iriarte & Lakhani) and adults with aphasia (Lakhani). Research methods evidenced across the studies were focus groups, participatory action research (PAR), sustained participatory engagement, nominal group technique (NGT) and photovoice. Whilst only one article (Davidson, 2015) outlined the co-creation of self-advocacy videos, Lorenz and Chilingerian (2011) described the use of photovoice or photo-elicitation to better understand patient preferences, Garcia-Iriarte et al. (2009) explored the use of participatory action research (PAR) and visual storytelling tools for capacity development and Lakhani et al. (2017) conducted a systematic review of the use of nominal group technique (NGT) to gain the perspectives of people with cognitive disability. Together these articles identified three key principles of relevance to the implementation of participant-led self-advocacy videos: (1) capability or strengths focus; (2) engagement strategies; and (3) feedback process.

Capability or strengths focus

The four articles each adopted a strengths-based approach. Davidson (2015) utilised the capability approach that focuses on what people can do, including their potential capacity. Participants are positioned as the producers, rather than consumers, of knowledge, as demonstrated in the process of co-creation of self-advocacy videos. Garcia-Iriarte et al. (2009) emphasised the importance of identifying both the strengths and needs of participants, and Lorenz and Chilingerian (2011) described a shift in perspective as participants shared their lived experiences and became 'co-experts' in partnership with their healthcare providers.

Engagement strategies

A key strength of all approaches outlined in the articles was engagement between participants and facilitators and between participant peers. Lakhani et al. (2017) identified a range of engagement strategies including: brainstorming with participants; training facilitators in information gathering techniques for people with cognitive impairment; and using multi-modal methods to gather information and ask questions. Davidson (2015) adopted an action research process that included the use of interviews to gather information about what the participants wanted to voice in their videos, co-construction of videos, viewing of videos together and focus groups. Lorenz and Chilingerian (2011) outlined a comprehensive approach to using questions to prompt visual exploration of participants' preferences and experiences.

Integration of feedback process

Two of the four selected articles introduced the role of feedback in supporting capacity development through both the experience of capacity validation and the opportunity to help others with a disability. Davidson (2015) integrated several feedback processes into the project including: viewing videos together, publishing videos on YouTube with use of the comments function, and a focus group to watch videos with peers and celebrate achievements. Garcia-Iriarte et al. (2009) described a cyclical process of action and reflection (praxis) with self and peer feedback to build group capacity.

2.2 | Lived experience workshops

As a partner in developing the intervention, the storytelling team at the advocacy organisation facilitated workshops to engage PWD and DSW in the project, as a preliminary step before the research pilot formally commenced. Twelve PWD (six males, six females), nine close others (six mothers, a father, a spouse and a brother) and six DSWs who accompanied participants with disability participated in the workshop. Disability types included ABI, stroke, cerebral palsy and progressive genetic disorders. The aim of the workshops was to capture experiences of 'disability support', to gather information about desirable DSW attributes and establish whether the PLV intervention resonated with people with lived experience of disability and support. Consistent with the practice of the advocacy organisation, the voice of PWD was paramount to the development of the PLV intervention.

2.2.1 | Procedure

Workshops were facilitated by staff at the advocacy organisation who had extensive experience facilitating storytelling workshops

with people with cognitive and communication impairments. To maximise engagement, the workshops were structured in three groups: (1) close others, (2) PWD who experience predominantly communication challenges and (3) PWD who experience predominantly cognitive challenges. Each workshop was conducted in a wheelchair-accessible location and was approximately 4 h in duration with rest breaks as needed. The workshops followed a process of group facilitation that encouraged story sharing, reflection and discussion. Reflections and suggestions were compiled, reviewed and revised by participants throughout the workshops and shared across the three groups.

2.2.2 | Results

During the workshops, PWD and families described how they were frequently frustrated by the lack of consistency and variable quality of the support they received. Participants reported that families and some PWD frequently spend significant time and energy training DSWs because of a high staff turnover rate. PWD want DSWs who are informed, skilled and trained to meet their specific support needs and preferences. Prior training and experience were noted as important, but not as important as a willingness to learn the person's specific needs and getting to know them as an individual. All workshop participants were highly engaged and enthusiastic about the development of an intervention that provides structure and support for PWD to direct and train DSWs.

3 | PHASE TWO: FEASIBILITY AND PILOTING

The PLV intervention was piloted by the advocacy organisation with the support of funding from the National Disability Services' Innovative Workforce Fund (Australian Government). The evaluation was conducted independently by university researchers and was ethically approved. The aim of the pilot evaluation was to gain an understanding of the experience, and satisfaction with, participating in the PLV intervention. The evaluation captured the perspectives of primary participants with ABI, close other participants who supported primary participants and staff who facilitated the video production process.

3.1 | Method

3.1.1 | Participants

The PLV pilot project involved 14 participants: five primary participants (four males, one female), five close other supporters (two family members, three DSWs) and four staff facilitators (see Table 1). The primary participants had ABI with resultant cognitive and communication impairments and high support needs. Verbal communication

TABLE 1 Participants' characteristics

Participant	Gender	Living arrangement	Complex communication needs
Primary participant	Male	SSA	Yes
Primary participant	Female	Home with family	Yes
Primary participant	Male	RAC	No
Primary participant	Male	Home with family	Yes
Primary participant	Male	SSA	Yes
Close other supporter (family member)	Female		
Close other supporter (family member)	Male		
Close other supporter (support worker)	Male		
Close other supporter (support worker)	Male		
Close other supporter (support worker)	Female		
Staff facilitator	Female		
Staff facilitator	Female		
Staff facilitator	Female		
Staff facilitator	Female		

was a substantial challenge for four of the five primary participants who utilised a range of strategies such as augmented communication devices, a whiteboard, gesture and assistance of close other supporters. One primary participant lived in a residential aged care facility, two in shared supported accommodation and two at home with family members. Close other supporters were family members or DSWs who had a long-standing relationship with the primary participants. Facilitators had substantial practice experience in either clinical or person-centred digital story production. All participants from the pilot were invited and consented to participate in the evaluation. Participants were provided with written information about the research, were reminded of the voluntary nature of their participation and assured of the anonymity of their data.

3.1.2 | Design and analysis

The pilot study evaluation used a mixed methods research design (MMR) (Teddlie & Tashakkori, 2010). The evaluation aimed to understand the experience of the PLV intervention and to measure satisfaction with the PLV intervention from the perspective of (1) primary participants with ABI-related cognitive and communication impairments, (2) close others who supported primary participants through the PLV intervention (close other supporters), and (3) staff who facilitated the video production process of the PLV intervention (facilitators).

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 enquiry when there is a relative lack of established information about the phenomenon of interest and researchers 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 thereby contextualise their lived experience of support whilst orientating them to the aims of the PLV intervention. Primary participants and their close others were also asked to rate their satisfaction and enjoyment with each component of the video production process.

One primary participant did not participate in the quantitative component of the evaluation due to physical pain and agitation that impacted data collection. 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.

3.1.3 | Procedure

Video production
The video production process was informed by the learnings of the scoping literature review and lived experience workshops. It included five steps: (1) goal setting, (2) scripting, (3) storyboarding, (4) filming and (5) editing. Primary participants were involved in steps 1–4, supported by the advocacy organisation staff facilitators. Allied health professionals, support coordinators and/or close others assisted in the planning and production of the videos, and editing was completed by staff at the advocacy organisation. Underpinning the PLV intervention was a commitment to maximising the participation of people with disability (primary participants) in all steps of the process.

Pilot evaluation
Primary participants and close others were interviewed and completed questionnaires in the home environment following completion of the video resources and viewing of the finished product. Facilitators were interviewed in the office. The semi-structured interview format was broad based and allowed for reflections across each component of the video production process. Primary participants were asked to consider and rate their knowledge of their own support needs, whilst both primary participant and close other interview questions explored the process of the PLV intervention. Interviews with facilitators explored more broadly the experience of facilitating the PLV intervention. Interviews were conducted by a university researcher who was independent from the PLV intervention and had extensive experience working in community neurorehabilitation.

All interviews were audio recorded and professionally transcribed. Written transcripts and researcher reflective journal entries were analysed using constructivist grounded theory methods (Charmaz, 2006). Analysis followed an iterative process of initial and focused coding ensuring that the data were grounded in the participants' experiences. The first author (JD) coded all transcripts with regular analytical discussions with the second author (KD). Utilising a process of constant comparative analysis, relationships within and across codes were explored, resulting in five themes that capture the process of PLV as experienced by the participants.

Customised rating scales were developed for the project to index four constructs from the perspective of primary participants and close others: (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 components; (iii) likelihood of recommendation of PLV to others; and (iv) overall usefulness of the PLV intervention. A 5-point response format (1 very low to 5 very high) was used for each of the scales except for the recommendation scale that used a rating from 0 (not at all) to 10 (very likely). Facilitators rated usefulness of the PLV and its contribution to the delivery of support in the sector on a 5-point scale (1 very low to 5 very high). Scales were completed with participants as part of the interview process, with use of a visual scale to facilitate the engagement of participants with cognitive and communication difficulties. Rating scale data were analysed descriptively for each participant group.

3.2 | Results

3.2.1 | Video production

Five participants with cognitive and communication impairments were supported by facilitators to produce PLVs. The videos range from 3.5 to 23 min long and include what the PWD participants wanted their DSW to know about them, how DSWs can support participants to do something and how participants would like DSWs to interact with them. Each PLV took between 5 and 15 h of paid time to produce, costing approximately $304–$3175. This cost calculation included labour time only for scripting, filming and editing and did not cover equipment costs.

3.2.2 | Pilot evaluation

Quantitative findings
Knowledge of support needs. Primary participants rated their knowledge of their ongoing support needs at a medium level (mean [M] 3.25, range [R] 1–4) and their knowledge of how to make plans for themselves (M 4, R 3–5), how they liked to be supported (M 4, R 3–5) and how DSW's need to support them to meet their needs (M 4.25, R 4–5) at a high level. In contrast, they rated their satisfaction with the support they had received in the past at a low level (M 2.5, R 1–5).

Satisfaction and enjoyment. Mean satisfaction and enjoyment ratings for primary participants and close others across each component of the video production process are shown in Figure 2. 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 others. Across components of the process, primary participants gave the filming experience the lowest satisfaction rating (M 3.75, R 2–5). Enjoyment ratings tended to follow the same pattern across components and participant groups with the enjoyment of the video product particularly high (primary participants R 4–5; close other supporters all 5.0).

Recommendation to others and usefulness of approach. When asked to rate how likely participants were to recommend PLVs for other people in similar circumstances, responses were extremely positive (primary participants M 8.33, R 7–10, close other supporters, M 9.63, R 8.5–10). Mean ratings of usefulness of PLV were also very high across the three groups of participants (primary participants M 4.7, close other supporters M 5.0, facilitators M 4.8).

Qualitative findings

Participant-led video experience (primary participants, close others and facilitators). Analysis of the primary participants' (PP) and close others' (CO) interview transcripts revealed that primary participants' experience of leading the production of their own support videos emerged as a personal development process beginning with the internalised structure of self, 'being me,' to an authentic externalised 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.* Whilst these thematic categories overlapped and co-existed 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 feedforward and feedback pathways between the starting and end points of the process.

Analysis of the facilitator data revealed similar themes to those of the primary participants and close others. Facilitators (F) reflected upon not only the experience, but also learning and recommendations from their experience such as modifications they made during the process, concerns about translation into practice and recommendations for additional improvements. Identified concerns centred around the skill levels of workers to implement PLV, the challenge of maintaining the currency of resources, as well as the potential inappropriate use of the PLV. For the most part, potential solutions involved mechanisms to upskill the disability workforce.

Knowing me and my support needs. Sense of self (who I am) acted as the structure around which primary participants processed their experiences and how close others 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.
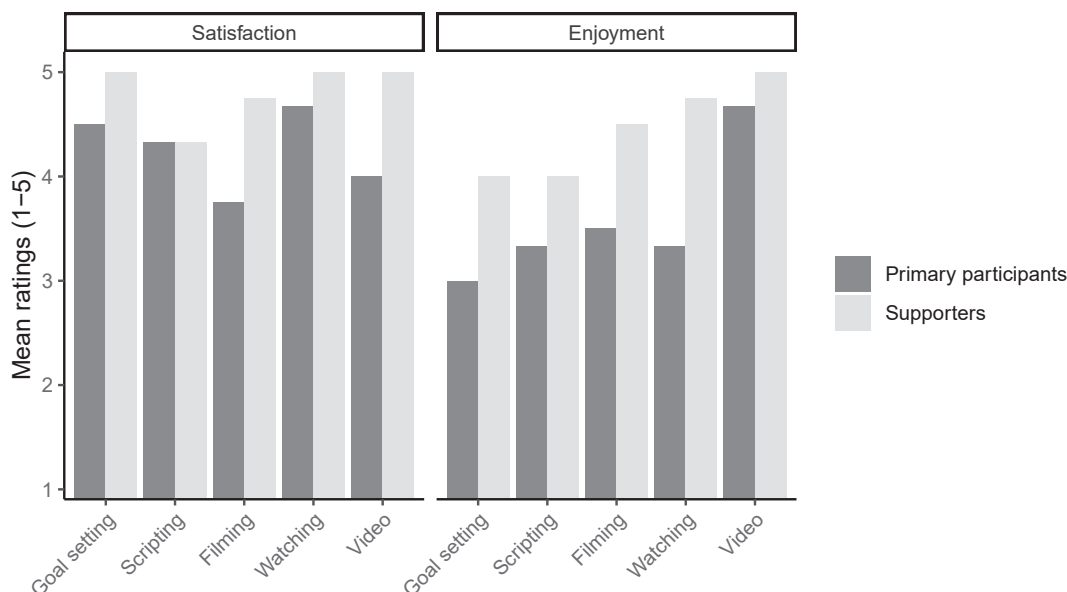

FIGURE 2 Mean satisfaction and enjoyment ratings for primary participants and close others
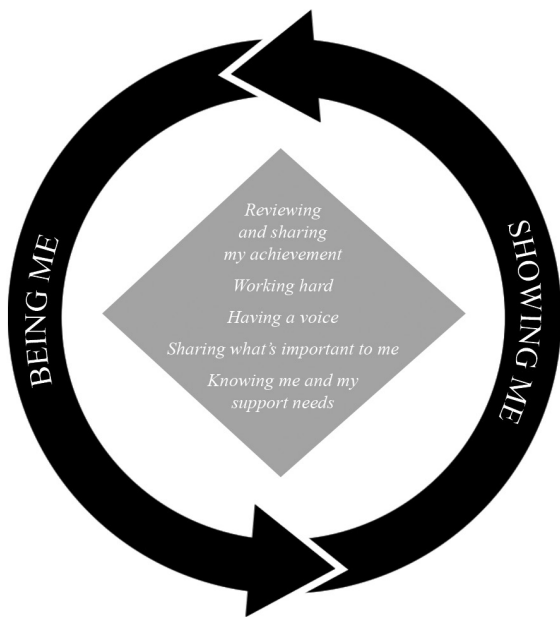
FIGURE 3 Participant-led video experience: From *being me* to *showing me*

> So they need to know what his needs are and everything like that, like who he is.
>
> (CO1 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.
>
> (CO of PP1)

> 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.
>
> (F1)

Sharing what's important to me. 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.
>
> (CO of PP1)

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

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.

> (F3)

Having a voice. For the primary participants, 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. Close others saw this consequence of the experience as particularly positive.

> 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.
>
> (CO of PP1)

> 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.
>
> (F2)

Working hard. Primary participants and close others 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)

> He does get a bit tired during the day—he has a couple of naps. ... It was particularly hard for him, it was tiring. ...
>
> (CO2 of PP3)

Reviewing and sharing my achievement. Working hard through filming culminated in a sense of achievement and a positive sense of emotional release and celebration was reflected in the experience of reviewing and sharing the produced PLV 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.

(CO2 of PP3)

When they put it on [produced video] 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)

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)

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

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.

(CO of PP2)

4 | DISCUSSION

This paper has described the development and pilot evaluation of a novel intervention to improve the quality and consistency of disability supports. The process followed the first two phases of the four-phase approach for development and evaluation of complex interventions described by Craig et al. (2008). These phases include: (1) development (scoping literature review and lived experience workshop), and (2) feasibility and piloting (independent mixed methods evaluation). The intervention provides a mechanism by which PWD can produce PLVs that inform DSWs about how they want to be supported. The pilot evaluation provides evidence of high levels

of satisfaction from all involved in the PLV process (PWD, close others and facilitators). 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 eight on a 10-point scale.

The scoping review indicated that there was limited research evidence to guide the development and implementation of participant-led support resources. Whilst capacity building and seeking the views of people with cognitive disability is increasingly understood to be integral to best practice, most research and interventions continue to use technology to educate or train PWD, rather than enabling PWD to use technology to have a voice in directing their lives (Davidson, 2015). However, the findings from the sparse literature that considers the value of adopting a participant-led approach to the development of resources, correspond with the pilot PLV evaluation findings. The experiential pilot evaluation 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'. 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 others and professional facilitators. Thus, this project further demonstrates the critical findings from the previous research including the importance of PWD 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 & Chilingerian, 2011). These findings are also consistent with a scoping review of personal narrative approaches in brain injury rehabilitation, which identified positive personal growth through feeling heard and validated through the experience of personal story sharing (D'Cruz et al., 2019).

The pilot evaluation revealed 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 participants to experience a shift in their goal setting from the more traditional position where, after variable levels of discussion, goals and support are imposed on a passive recipient, to the more progressive point of being 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 participate. 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 (D'Cruz et al., 2016; Plant et al., 2016; Prescott et al., 2019). The importance of 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 others and the facilitators. In fact, the facilitators noted an ongoing and pressing need to develop resources to support people with cognitive and communicative impairments to set goals.

The PLV intervention has the capacity to facilitate changes in support practice. As endorsed by participants in the pilot, PLVs provide a mechanism that enables support workers to see the person or the human individual, rather than the disability more readily. A move to a more 'humanising' perception has demonstrated the potential to reduce neglect and abuse in support and care situations (Galvin et al., 2018). PLV has the potential to serve as a personalised handover and training to new support staff, which some participants expressed to be better than a shadow shift in which new DSWs 'shadow' an experienced DSW to learn from observation. PLVs are also likely to reduce the burden that family members and significant others experience because of overseeing training of support workers.

4.1 | Limitations and challenges

Whilst this evaluation found many positive outcomes associated with the PLV intervention, these outcomes need to be considered in the light of limitations of the research. Only a small number of PWD and their supporters participated in this project. The PWD in the pilot study had substantial cognitive and/or communicative impairments and very high support needs, and the interviews were conducted after completion of the video production, potentially impacting the participants' recall of the earlier stages of the PLV process. Additionally, though the results of the pilot evaluation provide foundational grounds for scalability, the PLV intervention was only conducted with one group of highly motivated sector professionals. Therefore, there is a need to evaluate the process and its scalability across groups reflecting wider ranging characteristics. In addition, the evaluation was conducted over a relatively short period and does not reveal longer term outcomes and implications of the intervention. Systematic evaluation of outcomes beyond the development and implementation processes to longer term use of videos and impact on goal achievement is also required.

4.2 | Future directions

The PLV intervention and evaluation findings have been presented at several professional forums and conferences with encouraging feedback. People in the field of disability (academically, clinically and those with lived experience) have adopted the process and endorsed that the pilot evaluation findings reflect their experience. Central to the continuation of this work will be the training of sector professionals to support PWD to produce PLVs. Thus, the next step of this project is to train sector professionals and test the feasibility of PLVs in the community. In particular, the feasibility of lower technology options for video production such as use of a mobile phone for filming and editing. Consistent with the four-phase approach for development and evaluation of complex interventions described by Craig et al. (2008), following field testing, the plan is to implement a larger scale evaluation of the PLV, incorporating the perspectives

of PWD, close others and support workers. At this stage, a series of written and digital resources to guide the production of PLVs have been developed and made freely available online (Summer Foundation, 2019). It is hoped that the PLV training can be rolled out more widely to upskill a workforce that could support PWD to produce PLVs. However, there are potential pitfalls associated with inappropriate use of the approach and uninformed or erroneous interpretation of resources. Thus, further research is needed to demonstrate the skills required by disability sector professionals to support people with cognitive and communication impairments to document goals and produce an authentic participant-led training video to facilitate the delivery of quality person-centred support across the disability sector.

Though this pilot project provides good evidence around the development of the PLV intervention, appropriate use of the PLV is likely to be critical to its' impact on the quality of support. To maintain the currency of the PLV, it is important that it is updated in line with the person's needs and preferences. Additionally, PLVs have the potential to be used in multiple life domains, for example, directing DSWs, community-based rehabilitation or leisure activities, communication and monitoring goal attainment. Thus, future research is required to investigate how PWD use PLVs in practice, who is most likely to use PLVs and what impact does PLV use have on quality of support, outcomes and goal attainment. Findings from this research will inform the development of a resource to assist PWD in the ongoing use of PLVs to maximise the benefits of the intervention.

5 | CONCLUSION

Fundamental to quality support is the needs and preferences of the individual with disability. Key stakeholders including PWD, close others and facilitators have endorsed the value of PLVs as a viable mechanism for PWD to lead supports. Thus, the production and use of PLVs has much potential to improve the delivery of support and maximise support outcomes for PWD. The PLV intervention delivers a methodology through which several principles of the NDIS can be operationalised for individual participants, namely exercising choice and control, having the same rights as others without disability and to live free from abuse, neglect and exploitation (section 3[1]e; section 4[9]). Interventions like PLV clearly align with the principles of the Convention on the Rights of Persons with Disabilities (CRPD), supporting people to participate in decisions about their own life, and their support needs and preferences. Indeed, the results of this pilot evaluation indicate that PLVs are a feasible approach to enable people with cognitive and communication impairments to have choice and control, set their own goals and direct their supports.

AUTHOR CONTRIBUTIONS

Authors (JD & DW) substantially contributed to the conception or design of this study. All authors (JD, KD, DW, MT, CB & CF) each made substantial contributions to the acquisition, analysis or

interpretation of data for the work and were involved in drafting or revision of the work. Final approval of the version to be published was provided by JD, KD and MT.

CONFLICT OF INTEREST

The authors report no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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