



# Personalising Support through Communication between People with Intellectual Disabilities and their Support Workers

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## RESEARCH



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## ABSTRACT

Support organised through a personal budget aims to promote people's choices in how they arrange their support. Participation in choices of people who use little or no verbal speech to express themselves requires that support workers use personalised communication. This article explores how support workers use personalised communication to prioritise the choices of people with intellectual disabilities about organising support through a personal budget. It applies Gormley and Fager's framework of dimensions for personalising communication to analyse ethnographic data from four people with intellectual disabilities using personal budgets and their support workers. The analysis found that workers promoted people's participation in choices about their support when they focused on how people preferred to express themselves. Support practice, policy and research that target people's communication preferences in making support arrangements can have direct impact on their satisfaction with the arrangements and the quality of their personalised support.

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Personalised support for people with intellectual disabilities is intended to place them at the centre of decision-making about their lives and promote their self-determination in terms of how they want to live and receive support (Christensen 2009; Christensen, Guldvik & Larsson 2013; Christensen & Pilling 2014; Fisher et al. 2019). A personal budget is a funding and support model that can facilitate implementation of personalised support (Hall 2009). It consists of allocated money to a person based on an assessment of their needs and is intended to empower them (Christensen 2009; Horsell 2020). Their empowerment should happen by enabling choice and control about how to spend the money and deliver the support in personalised ways (Carey et al. 2018; Lutz 2020).

With reference to this purpose of personal budgets, part of a support worker's job is to provide personalised support to a person with disabilities by creating opportunities for their active participation in choices about support (Bigby & Douglas 2020; Shogren 2020). Active participation includes the person's preferences for directing the planning, organisation and doing of support arrangements (Lutz 2020). Facilitating this experience through personalised support arrangements requires that the support worker understands how the person expresses their preferences (Kelly 2016; Shogren 2020). They need to interact with people with intellectual disabilities and respond to their communication support needs in ways so they can voice their preferences effectively and arrange activities according to these preferences (e.g., Hemsley, Balandin & Worrall 2012; Hemsley et al. 2001; Iacono et al. 2019). Effective communication between the person and their support worker is therefore fundamental for personalised support (Forster & Iacono 2008; Iacono et al. 2019).

This article uses a case study approach (Hyett, Kenny & Dickson-Swift 2014) and draws on ethnographic data from four people with intellectual disabilities and their support workers. These data are from a study about the relationships between people with intellectual disabilities and their support workers (Lutz 2020). The study was conducted from August 2014 to March 2019 in Germany and Australia. The study explored support relationships in the context of support organised through personal budgets, consistent with international policy changes towards individualised funding and control (e.g., Cebulla & Zhu 2016; Pearson et al. 2020; Wacker et al. 2009). The analysis of four case studies applied Gormley and Fager's framework of dimensions for personalising communication. We draw implications for disability practice, policy and research that is guided by the preferences of people with intellectual disabilities through personalised implementation of communication support.

## COMMUNICATION SUPPORT IN PERSONALISED SUPPORT ARRANGEMENTS

According to Article 19 'Living independently and being included in the community' (United Nations 2006) of the Convention on the Rights of Persons with Disabilities, ratified by the German government in 2009 and the Australian government in 2008, people with disabilities have a right to receive personalised support. A personal budget is a support and funding model consistent with this right, which aims to personalise support by placing the person at the centre of their decisions (Fisher et al. 2019; Hall 2009). Depending on the type of personal budget and its associated goals, support workers can assist people with disabilities in their home and community to achieve this right in particular support areas (e.g., community participation, supported living, personal care and social relationships) through support activities (e.g., cooking, laundry and budgeting) (Christensen 2009; Guldvik 2014; Kelly 2016; Shakespeare 2014). Communication is one support area in the context of a personal budget and is of particular relevance for people with intellectual disabilities who use little or no verbal speech to express themselves.

Support workers assisting people with intellectual disabilities can sometimes feel challenged about how to understand the person's preferences expressed through non-verbal communication (Engelhardt 2021; Gomez-Victoria & Pava-Ripoll 2021). Time constraints to build this understanding or a lack of resources and knowledge about how to best provide communication support can contribute to challenges in support interactions (e.g., Dalton & Sweeney 2013; Hemsley, Balandin & Worrall 2012; Hemsley et al. 2001; Lutz, Fisher & Robinson 2016). Good communication support, however, is fundamental for the provision of personalised support that prioritises the person's participation in choices about the support and

aims to achieve self-determination (Iacono et al. 2019). Although communication support as an interactive process is a relational engagement, it is the responsibility of workers to provide good communication support during the engagement. They need to be able to understand the person's thoughts and feelings and support them to recognise and voice their preferences (Forster 2020; Gormley & Fager 2021).

Research has been undertaken to understand supportive communication between people with intellectual disabilities and their support workers (e.g., Bradshaw 2001; Dalton & Sweeney, 2013; Forster & Iacono 2008; Lutz, Fisher & Robinson 2016; Martin et al. 2022). This literature explores the potential of communication support, including augmentative and alternative communication (AAC), for people with intellectual disabilities within personalised support (e.g., Hemsley, Balandin & Worrall 2012; Hemsley et al. 2001). Little of this body of literature is about communication in support organised through a personal budget.

Several studies focus on support for people with disabilities using personal budgets (e.g., Christensen 2012; Graham et al. 2021; Guldvik 2014; Kelly 2016; Leece 2010; Leece & Peace 2010; Porter, Shakespeare & Stöckl 2021; Shakespeare, Stöckl & Porter 2018). Some studies consider aspects of the support relationship, including managing power in interactions (e.g., Guldvik 2014; Leece 2010) between support workers and people with intellectual disabilities using personal budgets, to understand how support organised through a personal budget can be improved to achieve its purpose for the latter (e.g., Fisher et al. 2019; Fisher et al. 2021; Lutz 2020; Robinson et al. 2021; Robinson et al. 2023). These studies conclude that support organised through a personal budget can influence the quality of support provision, but also indicate that people with intellectual disabilities using personal budgets are often not sufficiently included in decisions about their support arrangements. Further empirical evidence is needed about the perspectives of people with intellectual disabilities on their communication support and implications for how communication can be used to personalise their support arrangements. This article aims to add an empirical perspective by exploring the following research question: How do support workers use personalised communication to prioritise the choices of people with intellectual disabilities about organising their support through a personal budget?

## METHOD

We used a case study approach (Hyett, Kenny & Dickson-Swift 2014) with two cases each in Germany and Australia for variation in the influence on the person-worker communication of the different policy trajectories of personal budgets. In both countries, the disability service sectors transitioned to new policies about personal budgets, which include the National Participation Law 2016 in Germany and the National Disability Insurance Scheme Act 2013 in Australia. The policies created new contexts of support in the cases. People with intellectual disabilities were expected to actively participate in choices about their support by, for example, managing their budgets for support (Cebulla & Zhu 2016; Lutz 2020). This change influenced how personal budgets were administered to practically organise support in the cases (Carey et al. 2018; Horsell 2020). The case study method enabled us to analyse data about the interactions of four people with intellectual disabilities and their support workers within this policy context of personal budgets and contrast variations across the four contexts (Hantrais 2009; Hantrais 2014).

The ethnographic data used in this article were part of the data collected during a one-year ethnographic field study about support relationships (Lutz 2020). The study used Institutional Ethnography (e.g., Smith 2005; Smith 2006) as a research methodology to explore how policy processes affect the lived experience of people with disabilities and their support workers in their relationships and vice versa (Lutz 2020). The data in this article include ethnographic interviews with four people using personal budgets (Yelena, Jeff, Thomas and Felix<sup>1</sup>) and semi-structured interviews with support workers and service managers, field notes from a three to four week observation period in each setting and policy documents about the support. The observations were an unstructured form of participant observation (Balcom, Doucet & Dubé 2021) ranging from twenty-five to fifty-two hours across several days each week (Lutz 2020). For this article, we selected the four case studies because these four people encountered communication barriers that distanced them from decisions about their support (Gomez-Victoria & Pava-Ripoll 2021).

<sup>1</sup> All names of research participants in this article are pseudonyms.

Ethics approval for the study was obtained from the Human Research Ethics Committee from the University of New South Wales (UNSW) Sydney, Australia (HREAP 9\_14\_047 and HC15738). The field research in Germany did not require additional ethics approval from a German institution, confirmed by the German Association of Medical Ethics Committees and the German Ethics Council.

Recruitment of participants was through an ‘arm’s length approach’ (UNSW Australia 2015). This approach suggests that researchers make contact with their participants through services and trusted people to ‘avoid real or perceived coercion’, recommended by the Human Research Ethics Committee at UNSW.

The participants provided written or verbal consent to take part in the study. Participants with communication support needs gave consent in various ways (e.g., nodding, making a sound that implied approval or communicating agreement through a communication device) when they could not approve in writing or in addition to written consent (Lutz 2020). All legal guardians of research participants with communication support needs provided written and verbal consent. These were the parents of the participants.

Confirming consent continued throughout the ethnographic fieldwork (Cutcliffe & Ramcharan 2002; Rogers & Ludhra 2012). The researcher as a participant observer checked the participants were comfortable with the ways information was collected about them during the fieldwork. Finding out about their wellbeing happened, for example, by asking them or a person familiar with their communication support needs how they were and if it was okay if the researcher joined them in an activity. The interviews with people with communication support needs were part of the observation and facilitated by a communication device or a third person who was not the researcher or support worker and who was familiar with the person’s forms of communication. While the involvement of third parties, such as family members, was helpful for accessing participants, it sometimes introduced ethical challenges. A challenge, for example, included that their views and preferences about the person with disabilities’ involvement in the study were not congruent with the latter. The researcher’s ongoing critical reflections helped to notice these issues and sensitively resolve them through building trusting relationships and engaging in conversations with relevant people in the field.

The data were organised in NVivo and analysed against Gormley and Fager’s (2021) framework that influence the design and implementation of communication support. This framework consists of three dimensions (personal factors impacting the person-worker communication, environmental factors impacting the person-worker communication, strategies to personalise the person-worker communication) which we applied to the data in connection with the research question of this article. Within the three dimensions the data were thematically coded (Braun & Clarke 2014) as presented in the findings section. We introduce Yelena, Jeff, Thomas and Felix and then present the findings arising from the application of the analytical framework.

The four cases were specific to the individual support context and to a particular time of data collection. The case study approach is therefore limited in generalising findings to a larger population. Further research could extend the application of the analytical framework to a larger sample.

## CASE STUDIES

### Yelena

Yelena was a young woman in her mid-20s in Germany. She had physical and intellectual disabilities, used a few words, basic signing, facial expressions, sounds, body movements and sometimes wrote a text on her iPhone or paper notebook to communicate. Yelena had a personal budget for supported living, which paid for six support workers. Maria and Barbara were two of the workers and were a similar age to Yelena. Maria was a social work student and employed on a casual basis. Barbara was a permanent employee, social worker and Maria’s supervisor. Yelena lived by herself. She used a wheelchair and lift to access her apartment and a bus service to travel to places, such as to physiotherapy, speech therapy, work and her boyfriend’s place.

Jeff was a 19-year-old man from Australia who lived with his parents. He visited a day centre for adults with intellectual disabilities and high support needs four days a week. The day program participants were divided into three groups, consisting of four to six young adults. The Community Participation funding financed his attendance at the centre. Jeff used facial expressions and gestures to express his moods, as well as vowels, which he pronounced firmly and loudly, such as 'Nooh' (No) and 'Nana' (Banana). Linda and Maureen, who had disability training, were two of Jeff's support workers and permanent employees of the centre.

### Thomas

Thomas was a 26-year-old man from Germany who lived with four flatmates with disabilities (Moritz, Tanja, Steffi and Sandra). Luke supported them with cooking, shopping or cleaning. Luke was in his late 30s and had known Thomas for ten years. Thomas had two personal budgets, one for the support to live in his flat and one for a day program. Thomas had autism and intellectual disabilities. He was the only person in the flat who used one or two words to express himself. For deeper and longer conversations, he relied on his communication facilitator Robert. Luke and Robert were permanent workers with degrees in inclusive education.

### Felix

Felix was a young man in his mid-20s who was living with his parents, Margaret and Victor in Australia. He received two personal budgets, the Supported Living Fund and the Community Participation funding. Felix had autism and intellectual disabilities. He mostly used non-verbal forms of communication, but sometimes used one or two words to communicate. When he greeted someone he liked, he touched their hand gently and looked at them, maintaining a focused eye contact. Felix had six casual support workers with disability training. They were all near his age and worked with him on different days each week. Michael and Charlotte were two of them.

## FINDINGS ABOUT COMMUNICATION FOR PERSONALISED SUPPORT

The findings are structured according to the themes that emerged within the three dimensions of the Gormley and Fager analytical framework about personalised communication. This findings section starts with the factors about the person with intellectual disabilities that influence the person-worker communication, the person's attitude towards communication with their worker and their preferred ways to express themselves. The second dimension focuses on environmental factors about the worker's employment context that influence their capacity to engage in personalised person-worker communication. The third dimension constitutes strategies the person and worker use to personalise their communication with each other, which include formal and practical aspects of communication support as well as communication about support arrangements. The three dimensions are analysed separately, but in practice they are linked as person-worker communication is a relational process between people within a particular organisational arrangement and policy context.

### PERSONAL FACTORS IMPACTING THE PERSON-WORKER COMMUNICATION

The first dimension asks what personal factors impact on the communication between the person with intellectual disabilities and their support worker, such as the person's needs or preferences. The analysis found that the person's attitude towards the communication with their worker and their preferred ways to express themselves affected the person-worker communication.

The person's attitude towards communication with their worker was expressed in various ways. Yelena, for example, expressed her determination in communicating her preferences when she planned activities for the day and week, including transportation with the bus service. Her attitude affected her communication with Maria. During planning interactions, Yelena seemed patient and determined in getting her message across. Maria, in contrast, seemed frustrated about having to manage communication barriers.

Yelena typed a text on her iPhone and handed it to Maria. Maria raised her voice, 'Oh, Yelena, you're doing my head in—the transport service picks you up at 12?' Maria got it wrong and rolled her eyes. She seemed annoyed. Yelena continued typing. Maria asked, 'Tomorrow evening the transport takes you to Max's place?' Yelena firmly nodded, turned around and moved towards the bed, grabbed the telephone and handed it to Maria. Maria dialled a number. Yelena wrote on her iPhone. Maria turned on the speakers and communicated the written text to the woman. Yelena smiled and became joyful. (Field notes)

Yelena's perseverance emphasised that the organisation of transportation was of high importance to her. Transportation gave her independence to move about and visit her boyfriend Max. Maria's behaviour revealed feelings of agitation and impatience about her difficulties interpreting Yelena's communication, often shown in her tone of voice. Yelena's determined attitude led her to negotiate with Maria in a communication style that meant she retained control over her decisions about her transportation. This example demonstrates how the person's attitude to managing difficulties interacts with the worker's attitude and impacts on their communication.

Determination was also reflected in Thomas' attitude, but he communicated it in a different way to Yelena. When he experienced communication barriers, he expressed this by repeatedly distancing himself from the group. Separating was the way he communicated his frustration.

Steffi, Thomas and I [researcher] waited near the check-out inside the shop for Moritz and Luke. Thomas ran to another aisle and tried to grab a keyboard inside a box on a shelf. I asked him to come back. He eventually did. As soon as Luke and Moritz came back to us, Thomas ran towards the keyboard again. Luke firmly said, 'You have a keyboard at home, Thomas.' (Field notes)

Before and after entering the store, Luke did not converse with Thomas about what he wanted to buy. The frustration of not being included in group decisions might have led Thomas to separate from the group. This struggle within the person-worker communication arose due to Luke's difficulty interpreting Thomas' motivation to run away. The personal factor in Thomas' determination to communicate was linked to the worker's capacity to interpret the communication behaviour. Thomas had to run away to communicate what he wanted because he did not have other support from his worker that could have supported him to communicate his preferences at the shop.

Even when physical communication was the person's main means of expressing themselves, their physical contact was sometimes restricted by organisations' rules. One day, for example, Jeff and his group left the centre to have a picnic at a park, with Maureen supporting him.

On our way to the toilets inside the park, Jeff ran towards me [researcher]. Maureen stepped in between Jeff and me to hold him back. Jeff was about to put his arms around me. He was wild and hyped up from the running. His touch was firm. Maureen got angry and said, 'No, Jeff, you are not allowed to run away. That's very destructive behaviour.' Jeff shouted. (Field notes)

Behaviours such as touching or hugging people, were unacceptable in some organisations. This was a centre rule. In situations in which Jeff tried making physical contact with his workers, it did not seem that staff could consider his limited options to communicate his feelings in non-verbal ways. The physical contact rule was often incompatible with Jeff's communication interests, which included expressing himself physically through touch. This restriction had implications for his engagement in activities because he did not have other ways to communicate with his workers.

The person's choices about expressing themselves physically were also affected by the gender of the person and their worker. Physical communication and gender factors were evident in Felix' setting. While Jeff was forbidden to touch or hug any of his workers, Felix was allowed to do so with his male workers and to some extent with his female workers. For example, Felix expressed his liking physically for Michael through hugging or 'soft wrestling'.



When Michael arrived, Felix suddenly focused on Michael. Felix giggled and followed Michael around. Michael widened his arms and said, 'I am going to eat you.' Felix got excited and laughed. They jumped onto the sofa and grappled. (Field notes)

In contrast with female workers, Felix was expected to ask them first about hugging and could not do it spontaneously. Hugging seemed to be acceptable and occasionally happened when he followed this rule. The person's choices about physical expression influenced the person-worker communication. Their choices were dependent on the gender of the person with intellectual disabilities and their worker and the rules they worked under, which affected their physical closeness as a form of communication.

The personal factors influencing person-worker communication included how people could control how they communicated with their support workers about their activities. Their reaction to having control or restrictions on their preferred ways to communicate was reflected in their attitudes and actions. Having control over preferred communication affected their participation in choices about their support and activities.

## **ENVIRONMENTAL FACTORS IMPACTING THE PERSON-WORKER COMMUNICATION**

The second dimension of the framework asks how environmental factors influenced communication support in the person-worker interaction, such as staff knowledge and skills or healthcare continuum. A dominant factor of this dimension was the way the worker's employment context (work conditions, work history and roles) influenced the worker's capacity to understand the person's preferences.

The worker's role and employment conditions affected their familiarity with the person's preferred forms of communication. Prolonged work relationships improved the person-worker communication in a way that facilitated Yelena's expression about how she wanted her support delivered. Barbara seemed to know Yelena well enough to know that she needed to use closed-ended questions to support Yelena to make choices about her support.

Barbara asked, 'Chili Con Carne with pasta?' Yelena nodded. Then Barbara asked Yelena what she wanted to drink. Yelena indicated that she wanted cocoa by moving her head into the direction of the cocoa. Barbara got chocolate and strawberry cocoa out of the cupboard and asked which one she wanted. Barbara held the strawberry cocoa box up and waited for Yelena's reaction. Yelena nodded. (Field notes)

Differences in roles and employment histories influenced the development of familiarity with the person's preferred forms of communication. In contrast to Maria, Barbara seemed comfortable recognising Yelena's preferences. She gave Yelena time to think about what she desired and make a decision. Maria had only worked with Yelena for six months and was a casual worker. Barbara had worked with Yelena for many years. She was a permanent worker, had been Yelena's support coordinator and Maria's supervisor. This contrast in working relationship demonstrates how the work employment context affected the person-worker communication.

Employment conditions also affected the communication between Jeff and his workers. In addition to the no-touching policies, the centre's staffing rotation policy influenced the workers' capacity to familiarise themselves with Jeff's ways to communicate. The staff policy meant that workers rotated weekly across three groups and Jeff worked with different workers each week. Jeff could not use his personal budget to make choices about which staff he worked with. The centre's staff rotation policy restricted his communication because he could not choose to work with his preferred staff who understood the way he expressed himself. The staff explained that the purpose of the rotation practice was 'so they (program participants) don't get too attached to us and we (support workers) don't get too attached to them'. The manager Misty said that organising support in this way aimed to achieve greater flexibility for the participants and their workers, but the rotation practice made it difficult for Jeff to be understood. He had been at the day program for six months but needed to adjust to new workers each week. It also had implications for the workers, as it took them longer to familiarise themselves with Jeff's communication preferences. Policies that applied to all participants exacerbated the difficulties Jeff encountered trying to communicate to new staff. The work conditions did not take account of how people communicated and whether they received a personal budget.

The influence of the employment context on the worker's capacity to understand the person's communication preferences was also apparent in Thomas' setting. He had worked with Robert and Luke for many years, but only Robert used the supported typing method when he worked with Thomas. In the interview, Thomas navigated his responses via Robert who held his wrist to assist him in finding the right letter on a notebook keyboard to build words and sentences. Thomas stressed that he was very alone. In each quote, Thomas types, then Robert reads the text.

Researcher: Do you have friends who can help you not to feel alone?

Thomas: I do have friends, but to communicate gentle thoughts to them is difficult.

Researcher: What are your gentle thoughts?

Thomas: Gentle thoughts are confidential and intimate, one does not share with everyone.

Thomas explained that he shares intimate thoughts with Robert because he feels comfortable doing so and because Robert is familiar with the supported typing method. Thomas, however, could not share these thoughts with his flat mates or Luke, who were people he socialised with every day. He was often not fully included in decisions about his activities and when he was prompted to take part in them, his query was often dismissed, as the following situation shows:

Luke suggested buying nibbles. He asked Thomas, 'What do you want?' Thomas said, 'Sausage.' Luke responded, 'Shall we get cooked ham?' and looked at Sandra.  
(Field notes)

Thomas' budget funding for Luke was intended to have personalised the communication and facilitated his participation in choices about support. If Luke had used the supported typing method, it might have promoted Luke's capacity to understand Thomas' preferences more effectively. This might have helped Thomas to direct his support.

The worker's capacity to understand the person's preferences was influenced by their familiarity with the person's communication. Developing this capacity was either supported or restricted by the worker's employment context, including conditions, histories and roles. The worker's capacity to develop familiarity with the person's communication, however, had potential to support the person to communicate their preferences effectively. This effective person-worker communication then supported them to participate in choices about their support.

## STRATEGIES TO PERSONALISE THE PERSON-WORKER COMMUNICATION

The third dimension includes strategies the person and worker use to personalise their communication with each other and focuses on the customisation and design of communication support. These strategies included formal and practical aspects of communication support as well as communication about support arrangements.

Formal communication support involved communication in speech therapy sessions, such as received by Felix. He received speech therapy once a week for an hour, privately paid for by his parents. The formal arrangement included that there was always a support worker with Felix when Melanie, his speech therapist, worked with him. The interaction between Felix and Charlotte, his support worker, facilitated his engagement in the speech therapy activities.

Melanie asked Felix questions about body parts, such as 'Where are your shoulders?' or 'Where are your ears?' and to point at them. Charlotte walked to the back of the room. Felix followed. Felix watched Charlotte and copied her. Charlotte asked, 'Where is your chest?' Felix pointed at the lower part of his upper body. Then Charlotte showed him on her body where the chest is and he put his hands further up. (Field notes)

Felix was more engaged and happy when Charlotte joined in the communication with him as they did the activities together. Here, the person-worker communication was facilitated through formal communication support, which included that support worker and speech therapist work jointly with Felix. This joint method enhanced the shared communication learning beyond the formal session, into other communication about support choices.



Formal communication support included how communication support was documented and practically implemented by the worker. According to Thomas' goal agreement, a document that serves as a contract between the person with disabilities and the German government agency paying the funds (Lutz 2020), his budget was intended to support him in living more independently by providing him with communication options in his everyday life. His support plan listed the goals attached to his budget, which included 'sustaining the communication options within his environment'. Thomas' communication options were rather limited in his living environment though as he could not use the supported typing method there. Hilda, the service manager, explained that this form of communication support was not part of Thomas' support funded to live in the flat. It was covered in the budget for his day program, which encompassed Robert's support. If communication support through Robert was somehow integrated in the support at Thomas' flat and documented in the plan, he might have experienced better options of expressing his preferences and Luke might have had better opportunities to understand these preferences and adjust activities accordingly.

The importance of consistency between the documentation of communication support and its implementation in practice for the person-worker communication also became evident in Yelena's setting. Yelena's communication support included asking her closed-ended questions and using an iPhone to facilitate person-worker communication, but these practical methods were not formalised. The earlier described interactions between Yelena and Maria, as well as between Yelena and Barbara showed that these strategies had positive effects on the personalisation of Yelena's support, but Yelena's support documents did not list these strategies. Communication was not a formal goal of her support. The service manager Mathilda noted that Yelena's support needs were documented through an inquiry sheet that the service used internally. Communication was key to understanding what Yelena wanted from the support, but communication was not listed as a goal or sub-goal in the sheet. The overarching goal in Yelena's budget was living independently, with sub-goals about personal care, and eating and drinking independently. Yelena said in an interview that her goal was to move in with Max and spend more time with him. Poor communication between Yelena and her worker Maria about transportation made it difficult for Yelena to achieve this goal. This example highlights the interrelationship between recording the person's preferences about communication, communication support and support funded through a personal budget so that the person-worker communication is effective.

Consistency between formal communication support and the person's communication preferences also influenced the person-worker communication in Jeff's setting. In contrast to Yelena's situation, a technology-based activity via 'touch chat' was listed in Jeff's support plan and directed towards 'communication', a goal that he was meant to achieve when he worked with Linda.

Linda said the speech therapist suggested that he should use 'touch chat' on the iPad. Jeff touched a couple of icons on this App, then withdrew from the activity and watched 'Bananas in Pyjamas' on the YouTube App. Bridget (team leader of the centre) came into the room and prompted him several times to use 'touch chat'. Jeff firmly and loudly said 'Noooh'. (Field notes)

Linda was expected to encourage Jeff to use a specific communication App. Using the App was meant to facilitate his communication about what he wanted to do. Jeff did not seem to want to use the suggested App. He was interested in a different App. His preference was not consistent with the goal that Linda was expected to achieve when she worked with Jeff. This inconsistency in goals and preferences influenced the person-worker communication and compromised how Linda followed Jeff's communication preferences.

Communication about support work arrangements was important in team and planning meetings. Imogen, the team leader in Felix' circle of support workers, explained that Felix only attended every second or third meeting: 'He comes and goes but he's not so interested in sitting down and listening for two hours'. Margaret, his mother, explained that 'it's been too disruptive lately' and that this was the reason why Felix had not been attending the team meetings recently. It seemed that the way discussions and conversations occurred at this meeting were not set up to be inclusive of Felix' communication support needs. At these gatherings, however, discussions about the person using the budget, their activities and goals

were held and decisions about its organisation were made. Communication about support arrangements could have been set up for Felix using the Proloquo communication App on his iPad that he occasionally used.

Melanie said to Felix, 'Ask me a question on the Proloquo program.' He pressed the button, 'What did you do on the weekend' and waited for her response. (Field notes)

While Felix' workers might have advocated for him in these formal meetings and considered his preferences, his agency as a person using personal budgets was compromised when it came to decisions regarding his support due to not adjusting communication about support arrangements according to his communication preferences. This affected the person-worker communication, as Felix could not take part in the meetings.

The third dimension emphasised the importance of considering the formal and practical communication preferences for each person. Some people used assistive technology, for example, which was sometimes documented in the person's support plan and funded through the personal budget. Not all the workers used these communication supports, which hindered the effectiveness of the person communicating their preferences. These factors in the person-worker communication influenced whether the person's preferences directed their activities.

## DISCUSSION

The research addressed how support workers use personalised communication to prioritise the choices of people with intellectual disabilities about organising their support through a personal budget. The findings were that because people have preferred ways of communicating, these communication preferences are key to expressing their choices about their support. Some support contexts promote these communication preferences, where the workers and organisations seek out and attend to people's preferred ways of expressing their choices. In other contexts, workers and organisations do not prioritise their communication preferences. Some people's ways of expressing themselves need formal communication support, such as the use of assistive technology and its documentation. Some workers and organisations intentionally seek out and formalise communication preferences and communication support, so that other workers use these means of communicating choices. Attending to these three dimensions of effective communication has consequences for whether people can express themselves about their choices for support and be heard, so that workers, managers and organisations act on their choices.

This attention to preferred communication is particularly important for personal budgets where eliciting people's choices about support requires effective ways to express themselves. The analysis showed that when preferred means of communication are implemented, they enable stronger participation for people in their choices about their support. In these situations, workers encourage the person's preferred means of expression, so that they adjust their support to their choices. In these instances, the person's choices guide the support offered.

The findings about the dimension of personal factors in the communication framework showed the variations in people with intellectual disabilities' preferred ways to express themselves with their workers. People who expressed themselves physically faced restrictions from policies about safety. This finding about physical expression highlights the conflict between personalised communication and respecting physical boundaries. Gormley and Fager (2021) expand on AAC options for people with complex communication support needs, but do not explicitly analyse communication through physical contact. Findings about physical expression have implications for how disability support practice manages conflicting policy goals, while prioritising communication.

The analysis of the environmental dimension of the framework found that the worker's employment context influenced workers' familiarity with the person's preferences and personalised communication. Familiarity with the person was important for interaction that supported the budget holder to make choices about their support. Some workplaces had personalised communication material to facilitate expression. An implication is that communication can be enhanced by employment conditions that promote continuity in person-worker interactions. In addition, training and professional development can assist

workers to share their knowledge about personalised communication with other workers (Dalton & Sweeney 2013; Fisher et al. 2021; Iacono et al. 2019; Robinson et al. 2023). Sharing experiences may improve interactions through reflection. Gormley and Fager (2021: 13) consider communication training for workers. The analysis of these cases highlights the relational aspect of the person-worker interaction in training. This aspect suggests that training and professional development need to be inclusive of people with disabilities receiving communication support.

The analysis of the strategies to personalise communication dimension of the framework found that formal and practical aspects of communication support and communication about support arrangements influenced the person-worker communication. In some settings, the personal budget made a difference to how communication support was formalised, but in others, the budget did not seem to include formal communication support as part of the support. In the latter cases, people using personal budgets had little choice about their activities as conversations were organised in ways that did not consider their non-verbal forms of communication. These findings are similar to previous research (e.g., Dalton & Sweeney 2013; Gomez-Victoria & Pava-Ripoll 2021; Iacono et al. 2019). Gormley and Fager (2021: 6) comment in their framework about organisations' limited access to communication equipment and the limited availability of AAC tools tailored to meet the variety of communication needs. Similarly, the analysis in this article demonstrated that these limitations contributed to people having few ways to express themselves and therefore little choice about their support. The implication is that personalised communication could be enhanced through considering the use of assistive technology and drawing on the experience of workers familiar with the person's communication preferences. Insights from the experiences of people with intellectual disabilities using these supports could also contribute to a better understanding for support workers about the potential of technology and facilitating participation in decisions affecting their support (e.g., Martin et al. 2021; Ravneberg & Söderström 2017).

## CONCLUSION

Gormley and Fager's (2021) framework facilitated analysis of the quality of interactions between people with intellectual disabilities using personal budgets and their support workers. The three dimensions of the framework informed ways to understand how and if communication support was implemented in four support settings in which support workers assisted people with communication support needs. The first two dimensions focus on factors relating to the person or the worker within policy context. In practice the dimensions are linked. The environmental dimension has a stronger focus on the worker. This focus highlights the interpersonal responsibility of the worker to facilitate personalised communication through the factors in all three dimensions. The broad third dimension about strategies to personalise communication generates an overarching framework for formal and practical strategies to personalise the person-worker communication.

The three dimensions provide a lens to explore personalised communication on a micro-level of the relationship and interaction between the person and worker, and at the macro-level to connect to the policies affecting communication (e.g., worker's employment context, rotation policies, no-touching policies and formal communication support arrangements). The framework could be refined for future disability studies that emphasise the choices of people with intellectual disabilities. The second and third dimensions can easily shift focus away from their agency as people using personal budgets. The second dimension might not specifically prompt analysis of the personal preferences and agency of people with communication support needs.

Applying the analytical framework to the case studies identified variations in experience of communication support and policies. Even within the small sample, their communication experiences were diverse. Further research could extend to experiences of support interactions from a range of people with multiple disabilities and their workers from different age groups across a variety of support settings with different personalised support arrangements. In addition, we applied the framework to case studies from two countries, which provided insights into different support arrangements organised through personal budgets. Future research could extend the framework to settings in other policy contexts to further understand the impact of policies about communication and support arrangements of people using personal budgets.

Good communication support considers the three dimensions affecting the quality of person-worker communication. These dimensions are about the person, the environmental context and the strategies for communication. The analysis reveals that when disability support practice and policy focus on understanding the communication preferences of people with intellectual disabilities, they can actively choose how to arrange their support with their personal budgets. When workers attend to the three dimensions, people can express their choices and workers can act on these choices. An implication is that personal budget policies need to facilitate personalised communication in the process of making choices about support. Without attending to people's preferred ways to communicate, they have no means to make choices about how their support is arranged.

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The authors have no competing interests to declare.

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