Article

Impact of organisational practices on the relationships between young people with disabilities and paid social support workers

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Abstract

● *Summary:* This article uses Ikäheimo's concept of institutionally mediated recognition to explore how organisational norms and rules facilitate and constrain interpersonal recognition between a young person with disabilities and their paid support worker. The experience of recognition is important because it reflects the quality of this relationship and shapes the identity of both people in the paid support relationship. To understand the relationships between the pairs, Honneth's interpersonal modes of recognition were applied as the theoretical lens. The data were generated from photovoice, social mapping, interviews and workshops with 42 pairs of young people and their support workers in six organisations. These data were then analysed for the ways institutional practices mediated the interpersonal relationships.

● *Findings:* The findings revealed four practices in which the organisational context mediated interpersonal recognition: the support sites, application of organisation policies, practices to manage staff and practices to organise young people's support. Some organisational practices facilitated recognition within the relationships, whereas others were viewed by the pair or managers as constraints on conditions for recognition. Some young people and support workers also exercised initiative or resisted the organisational constraints in the way they conducted their relationship.

● *Applications:* The findings imply that to promote quality relationships, organisations must create the practice conditions for recognition, respond to misrecognition, and encourage practices that make room for initiative and change within the paid relationship. This requires supervision and training for and by support workers and people with disability.

Introduction

Research about the quality of the relationships between young people with disabilities and paid social support workers generally focuses on the experience of one of the members in the relationship or the organisational practices of the service provider, but rarely brings these elements together. This article analyses empirical data to explore the ways that institutional mediation affects recognition in these paid relationships. That is, how institutional norms and rules facilitate and constrain the possibilities for interpersonal recognition between the people in the relationship. Specifically, it applies Ikäheimo's (2015) institutionally mediated recognition framework to understand the impact of policy and practice on interpersonal recognition within the support relationship, as conceptualised by Honneth (1995) and adapted for the context of this research. The pair's experience of recognition is important because it reflects the quality of the relationship and shapes the identity of both people in the paid support relationship.

   The context in which paid support relationships are experienced is rapidly changing in Australia with the introduction of the National Disability Insurance Scheme (NDIS), the marketisation of support services and a policy emphasis on self-directed, person-centred care (David & West, 2017). These changes reflect international shifts towards individualised funding and direct payment schemes.They are consistent with the emphasis of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006) on the rights of people with disabilities to make decisions about what services they receive and how they are delivered.

   These changes have dramatic workforce implications, including increased demand for support workers, increased casualisation, and changing expectations of individually tailored and flexible support delivery (Macdonald & Charlesworth, 2016). Support is delivered in a variety of organisational contexts, as service provision shifts from government agencies to non-government organisations including advocacy groups, not for profit service organisations and private for profit companies (Carey et al., 2018). The proportion of people with disabilities and their families directly employing support workers is also rising (David & West, 2017). Each of these contexts not only defines the conditions of employment but also shapes the way the support relationship is understood and approached by people who receive and provide support (Guldvik et al., 2014).

   The problem that the research seeks to address is how people with disability and support workers can use the opportunities and constraints of the organisations within which they work to leverage changes in the policy context to ensure the quality of support.

   The article first describes the changing disability policy context, including direct funding, personalised support and workforce change. It then introduces recognition theory as a conceptual tool for understanding whether and how the support relationship creates the conditions for interpersonal recognition, and why this is potentially significant for both young people with disabilities and support workers. The discussion then turns to more recent theoretical developments around Ikäheimo's (2015) institutionally mediated recognition, which potentially extends understandings of support relationships and interpersonal recognition in organisational contexts such as disability services. Both theories are then applied to empirical data from research with 42 pairs of young people and support workers in six organisation sites. The findings draw conclusions about how the organisational practices facilitate and constrain recognition within the relationships and how the young people and workers accommodate and resist the constraints.

Background

Many high income countries are undergoing an important policy shift towards individualised disability support and increased control by people with disabilities over their services. In Australia, this shift has led to the introduction of the NDIS, a major reform to the social services landscape that aims to deliver increased choice and flexibility through individual funding packages that people with disabilities can

use to pay for services and supports to help them achieve personalised goals. At a macro level these policy shifts are welcomed as important steps towards achieving the vision for people's rights to decision making, community living and social, political and economic participation (CRPD, 2006). New service and business models are emerging, which 'have the potential to offer service users unprecedented levels of flexibility and autonomy in their support service choices' (David & West, 2017, p. 332). At an operational level, ongoing implementation challenges have the potential to disrupt the paid support relationship. These include uncertain employment conditions and highly variable levels of training and career development that characterise the disability support workforce (MacDonald & Charlesworth, 2016) and the additional support that some people with disabilities require to exercise choice and control in a market environment and participate in positive relationships with support workers and others (Meltzer & Davy, 2019). These challenges are overlaid by the financial constraints of support packages on the person supported and the organisations employing the support workers.

Paid support relationships

A key responsibility of disability services within this changing context is to implement policies that facilitate strong support relationships and mitigate any negative consequences individualised funding may have on working relationships. The international policy shift towards person-centred disability support highlights the autonomy of people with disabilities. But if applied in the extreme, autonomy potentially has adverse implications on support relationships (Guldvik et al., 2014), risking a reduction of the relationship to a transactional experience where it fails to recognise the interpersonal aspect of support workers' professional activities.

Previous research shows that when support relationships are grounded in reciprocity and mutual care and respect, they can be transformative for positive personal identity and social connectedness of people receiving support, and can promote job satisfaction and fulfilment for support workers (Lutz et al., 2015). As disability policies shift, the capacity for young people with disabilities and support workers to develop mutually positive relationships is increasingly important to ensure young people maximise opportunities that may arise with increased funding, flexibility and choice. In this context, it is equally important to consider the policy and organisational practices that facilitate and constrain the development and maintenance of these relationships.

While the more intangible or affective elements of the working relationship are determining factors in the satisfaction of people receiving and providing support, they are often overlooked in policy guidance and organisational rules about disability support. Support work, by its very nature, involves intimacies, emotions and social interactions that are not purely task related or instrumental (Palmer & Scott, 2018; Shakespeare et al., 2018). Indeed, the literature suggests that blurred boundaries (personal/professional, emotional/instrumental, colleague/friend) are a feature of support work. Blurred boundaries are sometimes described as a positive

feature of support relationships, leading to positive outcomes for the person with disabilities, increased fulfilment for the worker and creating 'a more equal and friendly relationship' (Williams et al., 2009, p. 620). However, these boundaries must be managed by the people in the relationship, which can be a demanding task (P. Fisher & Byrne, 2012) as both parties engage in emotional work to sustain the relationship in a positive way (Palmer & Scott, 2018).

Empirical studies of the relationship between people receiving and providing paid disability support remain under-theorised and under-researched (Hastings, 2010). Most studies have limited numbers of participants, focus either on people with disabilities *or* workers, and are either empirical or theoretical in nature but seldom both (see, for example Marquis & Jackson, 2000; Palmer & Scott, 2018; Prain et al., 2012). An exception is Banks' (2016) study of support worker–young person with disabilities relationships, which highlighted that interpersonal recognition in professional contexts promotes the growth of both people, extending understanding of support work and the ways in which organisations influence the interpersonal relationships. Another exception is Shakespeare et al.'s (2018) research into personal assistance in the UK, which involved interviews with people with disabilities and support workers. They found that the direct payment system profoundly influenced the support relationships and particularly the interpersonal power dynamics between people with disabilities as employers and support workers as their employees. Despite this, there was a wide spectrum of ways people defined and interpreted their support relationships, including paid friends, staff and quasi-family (Shakespeare et al., 2018), with different identities associated with each.

The paid support relationships of young people with disabilities are often overlooked in research as the identities of the young people and support workers are easily reduced to the role they play in the relationship rather than focusing on the relationship itself and the potential this relationship holds for creating the conditions for recognition to occur. It is important to acknowledge that for some people, these relationships are just one of many, whereas for other people, they are key to extending their social networks beyond the family and building confidence and positive identity (Romer & Walker, 2013; Skär & Tamm, 2001). Hence, in researching the support relationship through a recognition lens it is important to bear in mind that differences in the nature, experience and significance of support relationships for both young people and support workers, together with different organisational contexts, are likely to affect the experience of interpersonal recognition.

Linking interpersonal and institutionally mediated recognition

Axel Honneth's (1995, 2001, 2004) theory of recognition lends itself well to a study of paid relationships between young people with disabilities and their support workers. Its potential lies in Honneth's focus on the critical importance of human interaction (relationships) for personal and social recognition. Given recognition theory has its roots in critical theory, with evident links to social justice,

its practical application as a theoretical and analytical tool within human service and social work settings is gathering momentum (Graham, Powell, et al., 2016; Niemi, 2015; Rossiter, 2014).

Honneth (1995) argues that recognition is essential to self-realisation and the 'cumulative acquisition of self-confidence, of self-respect, and of self-esteem' that, in turn, allows the person to come to know and see themselves, unconditionally, as both 'an autonomous and individuated being and to identify with his or her goals and desires' (p. 169). In this way, Honneth posits that identities are not only socially acquired but also a matter of justice because the acquisition of self-confidence, self-respect and self-esteem is the foundation of autonomy and agency (Rossiter, 2014). Honneth identifies three modes of recognition necessary for an individual to develop positive relations-to-self. These are love, rights and solidarity (Honneth, 1995, 2007). 'Love' refers to emotional concern for the wellbeing and needs of another. 'Rights' reflects respect for the other party's legal status as a person and citizen. 'Solidarity' refers to the valuing of an individual's particular traits and abilities, and the distinctive contribution these bring to a community (Honneth, 1995). Drawing on earlier research grounded in the theoretical underpinnings of Honneth's work and adapted to studying relationships in organisational settings (Graham, Powell, et al., 2016; Graham, Truscott, et al., 2018), the three modes are articulated here as 'cared for', 'respected' and 'valued'. These modes or patterns of interaction hold potential to conceptualise interpersonal relationships between young people and support workers (Blonk et al., 2019; Niemi, 2015).

Ikäheimo's (2015) work on institutionally mediated recognition adds an additional, crucial dimension to this analysis by highlighting how the institutional context, including the paid nature of the arrangement, affects the potential for and nature of interpersonal recognition. In order to distinguish and identify the impacts of institutional context on the interpersonal relationship, Ikäheimo (2015) uses the term 'horizontal recognition' to refer to interpersonal experiences of recognition between the pair and 'vertical recognition' to refer to the mediating effects of institutional norms and practices on the pairs' experience. These are useful concepts to draw on when analysing a situated interpersonal relationship that is also a professional paid one. For example, vertical recognition can occur through an organisation recognising the rights and personhood of people receiving support in organisational policy, or a workplace culture that encourages respect. Horizontal recognition between people with disabilities and support workers does not occur in a purely intersubjective vacuum, but is shaped by the formal and informal rules and norms established by this institutional context. Thus, promoting the conditions for recognition through institutional practices is crucial for quality support (Ikäheimo, 2015) since institutional practices of recognition can facilitate solidarity within, and consolidation of, personal and professional identity that enables both people in the support relationship to exercise their agency.

This article explores the ways in which recognition is experienced between young people with disabilities and support workers, extending Honneth's *interpersonal recognition* by applying Ikäheimo's framework for institutionally mediated

recognition to better understand the impact of context on interpersonal relationships. This article refers to the concept as *organisational mediation* to focus on the paid relationships in disability organisations, as distinct from institutions as places where some people with disability live. The distinction also avoids the overlap with the various meanings of institution from institutional theory across many disciplines.

The research used qualitative methods to further develop an understanding of the ways in which organisational mediation impacted positively or negatively on the relationship between young people with cognitive disability and their support worker within organisational settings.

Methods

The data were generated from participatory research activities with 42 pairs of young people with cognitive disability and paid support workers in six non-government organisations. The organisations employed the support workers and organised the support. They varied in location and size (Table 1). The organisations had all operated for more than 15 years and offered support mainly for community access, housing support and personal development. The organisations employed and supervised the support workers, who were paid under the national standard industrial conditions. Most workers were vocationally trained and supervised by a manager with similar qualifications.

Table 1. Characteristics of the participant pairs and support context.

	Participants (42)		Young woman	Young man
Support worker	Woman	28	21	7
	Man	14	2	12
	Total	42	23	19
Years working together	Less than 1	15		
	1–2	14		
	3–4	4		
	5 or more	6		
	Unknown	3		
Support context	Group	27		
	One to one	12		
	Mixed	1		
	Unknown	2		
	Organisations (6)			
Location	Urban	3		
	Rural	3		
Number of people supported	Less than 100	3		
	100 or more	3		

Note: Qualitative sample of pairs of young people with cognitive disability and support workers employed in six organisations in three states, 2016–18.

The support was provided to young people in small groups or individually by the support worker in their research pair. The time spent together varied across the organisations and between the pairs. Within the study young people with disabilities who agreed to participate were asked to nominate the support worker with whom they would like work. Once a support worker was nominated they were asked if they would be willing to participate in the study with the young person. A limitation of the study is that in a small number of cases, organisations allocated regular support workers to young people based on rostering or organisation rather than seeking their preferences.

The research was approved in March 2016 by Southern Cross University's Ethics Committee. The research was discussed with young people attending the six organisations where the research was based. Expressions of interest were passed on to the researchers who discussed possible participation with each young person. An accessible booklet about the research and accessible consent forms were developed for young people and their families. An invitation based on the preferred worker of the young person was given to a prospective support worker participant (often facilitated by the organisation). If they agreed to work with the young person on the research they were provided with an informed consent form. For both parties the consent forms had information about the data to be collected and ensured that confidentiality would be maintained.

Mixed qualitative methods were used to generate data from the pairs individually and jointly. Each pair was involved in a joint interview in which they socially mapped what they did together and their social interactions. Following the mapping exercise individual interviews were held with the young person and the support worker. All joint and individual interviews were recorded and with permission from both members of the pair selected photographs were kept by the researchers. Photovoice was used where each pair together took photos over a period of between 12 and 16 weeks, captioning and uploading this material to the researchers (Jurkowski, 2008), and then through follow-up interviews ranking and discussing the significance of the images and captions both individually and together with the researcher (Clark, 2012). Individual interviews were held with the manager of each organisation with a focus on the policies and practices in relation to individualised support and staff supervision. Much of the data were collected at the organisation, facilitated through organisational support to recruit participants and provide private spaces for interviews and social mapping exercises. Other data were collected in the person's home or community. Collecting data onsite was an opportunity for researchers to observe practices of organisationally mediated recognition (or its absence) and to understand how the layout of the site and its connection to broader community location mediated the relationships. The researchers also recorded their reflections of the data collection, including organisationally mediated recognition in the pairs.

All written and visual data were coded by two researchers using NVivo software against the themes derived from the conceptual framework. The analysis for this article sought evidence of the impact of organisational practices that facilitated or

constrained the conditions for interpersonal recognition within the relationship between the young person and the support worker, and their reaction to these practices.

The entire research team participated in the analysis using Neale's (2016) process of iterative categorisation. The process is a systematic technique for analysing qualitative data and 'a route back to the raw data for further clarifications, elaborations and confirming/disconfirming evidence' (Neale, 2016, p. 1097). Applying iterative categorisation encouraged the university researchers to articulate the preliminary findings in concrete terms to facilitate discussions with the co-researchers with cognitive disability and practitioner researchers who contributed to further data analysis. It also enabled checking with organisation managers, staff and representatives of people who use disability services through workshops about the preliminary analysis.

All names are pseudonyms. Fewer quotes from young people are included because some people had high support needs and communicated using methods other than spoken language. Instead, their experiences are included in descriptions from the mixed methods data. The quotes were selected as examples of trends in the data. The characteristics of the research participant pairs are described in Table 1.

Typically, participants were involved in structured programs, which they selected through individual planning. The programs centred around life skills for independent living, community participation for social skills, transition to work and job skills, work experience, group activities or excursions and respite. Most pairs (n = 25) spent one or two days per week together in paid support; and the others spent more time together. In addition, many of them said they incidentally saw each other on other days if they were at the organisation working with someone else.

This article is part of a larger study (Young People with Cognitive Disability: Relationships and paid support) that analysed the data using Honneth's three modes of recognition. It found that the importance of interpersonal recognition is evidenced in the relationships between young people with cognitive disability and paid support workers (Robinson, Blaxland, et al., 2020; Robinson, Graham, et al., 2020). The larger study found that the organisational context positively and negatively influenced how these relations were experienced. This article extends that earlier finding by examining the practices in which organisational context affects relationships.

Organisational practices that facilitate or constrain recognition

The analysis revealed rich insights into the ways the organisational practices influence the relationship and mediate the conditions for interpersonal recognition. It identified four practices in which organisationally mediated recognition was particularly evident in the relationships: support sites, application of organisation policies, practices to manage staff and practices to organise young people's support. Some organisational practices facilitated recognition within the relationships, whereas others were viewed by the pair or manager as constraints on conditions for

recognition. The young people and support workers also exercised agency in resisting the organisational constraints they faced. The practices in which the organisationally mediated recognition operated, along with resistance to constraints are evidenced below.

Support sites

The findings demonstrated that some characteristics of the support sites facilitated conditions for interpersonal recognition. Typically this occurred through spaces conducive to interaction in the sites; enabling spaces that supported the activities of young people, including resources and functionality; movement across and within locations; and community inclusive spaces.

The sites of the organisations mediated the way young people and support workers related to one another. In some instances organisations had spaces where informal relationship development could take place alongside goal-focused activity. For example, one pair spoke at length about their mutual love of music and the music studio in the service meant they could play music together and teach other people who used the service. The young man, with few words, became very animated speaking about this: 'Yeah, drumming at [organisation]. Drumming out the back studio. Drumming out the back. Me, Ernie. *[So, going out the back together and doing drumming?]* Makes me happy. Yeah. Ernie and me out the back drumming' (Tony, young person).

The proximity of an organisation's site to the broader community was an important element in mediating recognition in the pair's work together, through encouraging social inclusion or acting as a barrier to the young people to access community spaces such as local cafes and shops. One organisation had several hubs within walking distance in the local community for different parts of the service. Not only did the trips between the hubs enhance their feeling of community belonging, but also the different hubs encouraged people's preferences and strengths. One pair captured the positive impact of this mediation well describing their routine:

> *Julie:* And then we have the best time of the day, don't we – because then we walk all the way down ... to the hall – and as we go, we talk ... and we say hi to people in the street. *Jennifer:* Yeah. *Julie:* If we meet up with a busker, we stop and have a song with them – because all the buskers know [you]. *Jennifer:* Yeah. (Julie, support worker; Jennifer, young person)

Some sites had a hierarchical approach to service provision, which had the effect of limiting the ways the pairs related to each other at the site and in the community. One site had formal learning and socialising spaces with little or no contact with managers upstairs. Some organisations restricted the use of public spaces, which constrained where and how the pair interacted. One support worker explained the

impact of a managerial decision to restrict access to local shops because of the cost, as well as their resistance against the rule:

> [New] rules been brought in, support workers are niggling away at this, we'll sort it out for the guys, but they can no longer have the choice to go and buy their lunch every day . . . that is also taking the guys out of the community . . . they've got established relationships with people in different shops . . . they're being confined to the house more and more. (Jason, support worker)

Some pairs resisted the constraints by avoiding the site of the organisation. They changed their routines and kept out of the centre as much as possible to keep 'under the radar', maximising the time they had together on the activities that the young person enjoyed, rather than managing competing demands and administrative practices at the centre before they could set out on their day. This approach had costs for support workers, such as starting work earlier to smooth the path, collecting a vehicle and checking in with managers. The fact that they were able to manage this tension suggests that the organisations accommodated the approach at an individual level. But it seemed to rely on the initiative of the worker and did not appear to indicate any organisational adjustment so that the pair and others were not constrained by the conditions at the site.

Application of organisational policies

The second practice relevant to organisational mediation was the application of organisational policies. Most support workers and some young people were aware of organisational policies that mediated the conditions for their relationship. The policies were mainly ones that affected the ways that the pairs could enact their relationships and move about the community together, such as rules about rostering, choice of worker, use of transport and ways that young people's choices were enabled.

An example of how policies influenced relationships and mediated the conditions for interpersonal recognition was the degree of organisational flexibility in managing contact between the young person and support worker. Perspectives about whether these policies benefited their relationships were mixed. Some people described how the policies that allowed flexible communication were important for responding to young people's needs:

> I think we can be more responsive with technology; we can step in a lot faster; they can let us know when something's going wrong, very quickly now . . . I can respond to [someone] at the point of time that [they are] distressed. (Beverly, support worker and service manager)

The support worker and the young person she supports included a photo of text messages between them in their photo research, and spoke about how they

increasingly relied on text messages in their working relationship, even when the young person preferred communicating more directly:

> *May:* We don't see much of every other and we don't sit together and [text] is how we communicate now. *Beverly:* I see texting as important, because it shows something different in our relationship. *May:* I think it is a little bit easier [to talk] in person. Like, if it is personal, I would come here and talk face to face. (May, young person; Beverly, support worker)

The pairs had a range of agreements about communication, in most cases determined by support workers, in some cases mutually agreed and rarely initiated by young people. At times, this left young people frustrated about their lack of capacity to initiate further interaction in the same ways as they did in other parts of their lives. One organisation had a policy that after work hours, support workers were not contactable and a message could be left for them through the organisation. Young people, with the support of one organisation, invited staff to join a closed Facebook site to allow more informal and irregular communication and to overcome their frustration about contact outside their support time.

> These guys have designed a group on Facebook and have asked the staff – they can write things up on the post and we can answer . . . It's just fun stuff. If these guys have ideas on where they want to go for social things, they can post it. (Charlotte, support worker)

Despite organisational policies, many pairs readily discussed making their own contact arrangements depending on what best suited their relationship or the young person's needs. Organisations appeared to turn a blind eye to contact arrangements contrary to their policies, with no mention by participants of any repercussions. The quotes below from the same organisation demonstrate the contrasting approach to resisting the organisation's policy discouraging private contact, social media connection and sharing mobile numbers:

> It's [social contact] a personal thing. (Dylan, young person)

> He's got my phone number and I had to explain to him that that was for important things . . . but he does understand and he's stopped ringing all the time which is good. Mostly text. (Michelle, support worker)

> He and I have got a really close relationship and he tells me everything . . . He's got my phone number so he can call me out of hours if there's any issue that I can help him with. (Robert, support worker)

A manager of one organisation reinforced that staff controlled the initiative about following the contact policies. She discussed how support workers could negotiate

contact through social media:

> We put it out to staff that they can choose. So whether they accept clients as friends on Facebook, but they need to recognise the implications of that...Some staff have made the mistake of friending clients on Facebook and then getting upset that their clients suddenly know all about their personal life. (Beverly, support worker and manager)

While some organisations had policies in relation to communication between young people and their support workers, it seemed that the form and amount of contact was left to the support worker's preference and initiative. There was little evidence that the young person had input into how it was organised. In some instances their preferences were taken into account but it was at the initiative of the particular support worker.

Practices to manage staff

The third type of practices where organisational mediation was evident was those for managing staff. Staff management practices were generally responsive to young people's preferences to ensure they worked with their preferred support workers. Organisations often had mechanisms by which the young person or their families could request particular workers in one on one support relationships. Some young people were confident that if they wished to work with a particular support worker, they could ask a plan manager for this to occur.

> [How did [worker's] name come up? Was it suggested to you?] I suggested it. But also suggested the second one, said a second name as well. [So you think it's good having a bit of variety and not working with (worker) all the time?] Yeah. (Caitlin, young person)

Access to staff within program hours through rostering or informal interactions when not working together was usually managed to the benefit of the young person. In some organisations, the proximity of the staff rooms to group areas meant that support workers who had a particular rapport with a young person were often on hand, even if not formally rostered together, and available if the young person was distressed or having difficulty. In practice, this meant that support workers supported each other and the young person as needed. It reinforced the findings about the importance of the layout of the organisation site to encourage incidental interaction.

However, the way staff were managed did not always facilitate conditions for strong interpersonal relationships. Support workers gave examples of how some policy about staff practices constrained relationships, such as policy to avoid long shifts, which prevented weekends away. Some staff discussed frustration with lax

practices for staff handover between shifts or poor communication between services that affected their relationship with the young person.

Young people felt the negative impact of these staffing practices. High turnover of support workers troubled some of the young people. They spoke about the impact of support workers leaving, particularly when they left without saying goodbye, which happened twice during the project. This distressed the young people affected, who felt disregarded. They spoke about stress that resulted from loss of a support worker:

> I'm not [scared] but sad when people move to another place. *[Why does it make you sad?]* Because you don't see them that much or [they're] gone. *[Yeah. No, that's important]* And I don't want that to happen to Susan. I'll just get stressed. (Lucinda, young person)

Many examples of young people and workers' resistance to the staffing constraints were evident. Some young people chose activities because they preferred the support worker who ran them, rather than because of their interest in the program. Several pairs worked out how to avoid too much change when they valued each other's company and how to bend the rules that did not allow support for activities they preferred. One support worker developed a work experience placement in response to the interest expressed by a young person, even though it was outside her work role. With his agreement, they extended the opportunity to a second young person who had no funding to cover the costs of the support. Another worker travelled with a young person to see a concert, although this meant an overnight stay, which rostering policies did not allow.

Organisations seemed to be supportive of pairs using their initiative to make decisions about time spent together, where their time together was restricted, such as by transport, rostering or proximity to where they wanted to go. In many instances support workers said they went beyond their roles and rostering at their own cost to have contact and make arrangements outside of their planned activities with young people.

Some workers were less certain about the focus of their role, and this affected the range and quantity of contact they had. Support workers who were less clear about the purpose of their support did not seem to seek to build new opportunities with the young people. This situation relied on the young person initiating change:

> Well I'm only – I am actually his key worker, as far as what my role is with that I'm not certain...I just want to help him because he asked for it, so if I can help I do. (Michelle, support worker)

The general sense was that organisations tolerated young people and support workers bending the rules if it was perceived to be in the interests of the young person. This resulted in some inequity for young people who did not work with support workers who took this approach. In general, the young person had to rely

on a support worker who was prepared to lobby on their behalf for them to organise their time together. It also had implications for the work conditions of the support worker, including unpaid time.

Practices focused on the young person

The final practices affecting organisational mediation were those focused on support for the choices of the young person. Organisations had varied approaches to organising support for young people and typically encouraged support workers to be flexible and responsive to the needs and preferences of the young person. This was exemplified in support workers organising community based activities from the young person's preferences:

> We like to walk around Westfield, we like to go and have a coffee...and have a look...because they said 'You guys have the afternoon free' and we're just like going – wow great, what are going to do? (Amy, support worker)

Only a few young people said they controlled the decisions about how their support was organised and activities they could pursue rather than the worker:

> [So when – how do you decide whether you want to do it? Does [the support worker] mention it?] No. I do. [You come up with it?] Yeah. [So it's all your choice?] Yeah. [Do you like feeling like you're in control?] Yes. All the time. (Caitlin, young person)

Support workers discussed how organisational practices enabled them to respond to young person's preferences. They said they could act on the young person's preference if it was within the parameters of current programs or if the support worker persisted with enabling a young person's choices. A support worker described how a young person would initiate a goal and they would help action it:

> So for instance if he's wanted advice on relationships...he'll make a suggestion or he'll go, "This is what I want to do"...and then what we do is we plan time to talk about that...Then we go, ". . . So how do we go about it? Is there going to be consequences about it?". (Charlotte, support worker)

The organisation's approach to individualised support framed the capacity of the pair to interact responsively to the young person's choices. Where organisations had formalised individual support practices, young people and support workers observed that the practices facilitated their capacity to act on their choices through focused plans. Some young people were aware of the planning practice and focused on working with their support worker towards goals: 'I'm learning with [worker's] help how to defrost food quickly and safely and new cooking recipes. This means a lot to me as I want to end up cooking independently' (Sophie, young person).

The benefit to the quality of their relationship was that the practice provided a structure for the worker to express respect and value the young person's choices. The risk was sometimes the support was transactional, with less room for spontaneous interactions. In other organisations, goals set with young people were general, which left lots of initiative about what they did, but did not necessarily focus on what the young person wanted.

Some organisations offered support to young people through choices from a selection of program activities, rather than individualised support. Others pointed to new business practices that resulted in more centre-based, less individualised support. These practices restricted young people's decisions about support to a limited set of group options. The pair was not able to resist these types of organisational constraints on activities, which affected what they did together and presumably how they did it. '[*Were you interested in it?*] Oh, I was just following the plan. [*What other programs would you like to do, if you got to choose, besides your sport and your bowling?*] No idea' (Scott, young person).

Many support workers also discussed the constraints from organisational practices on how they worked with young people, preventing them from realising their potential. In part, they said an organisational problem affecting the quality of their support relationship was limited time to plan, review goals and evaluate decisions with the young person. They felt they did not have adequate supervision and training for reflective practice and deliberate communication with the young person to explore change. They were concerned that where they supported the young person within constrained program options, they could not support them to consider broader goals such as work experience. In this organisational context, it was difficult for the pairs to focus on capacity building to identify and work towards individual goals.

The pairs also demonstrated resistance to organisational constraints on the young person's preferences. A support worker found the young person he worked with was excluded from the opportunity to participate in work experience because of his disability. The worker rectified it by managing the tasks within the role so that the young person could instruct the worker to do the physical aspects of the job he was not able to complete. His approach enabled the young person to participate and feel included in opportunities available to others.

The organisational response to initiative from the pairs such as this usually seemed to be supportive. Organisations generally encouraged or did not oppose strategies employed by support workers and young people to work around restrictions. Equally though, they did not seem to formalise or amend policy or practices to accommodate the approaches.

Discussion

The analysis of disability support in these organisations demonstrates that relationships between people receiving and providing paid support are mediated by the organisational context. It highlights the role such mediation plays in shaping the

relationships and hence the conditions for and experience of interpersonal recognition, consistent with Ikäheimo's (2015) theorisation. Specifically, the findings underline the critical importance of engaging more closely with organisational practices that tacitly and explicitly create conditions that enable or constrain experiences of being valued, respected and cared about through the paid relationship (Robinson, Graham, et al., 2020). Examples of when organisational practices fostered interpersonal recognition included policies that allowed initiative in decisions between the young person and worker, which enabled them to negotiate the young person's preferred focus of support, simultaneously creating opportunities for mutual valuing, respect and care to emerge.

Not all organisational practices facilitated such conditions, with some actively constraining the possibilities for interpersonal recognition. We identified four mediators that merit close attention in understanding the role of organisational practices in limiting or enabling mutual valuing, respect and care: the support sites, the application of organisation policies, practices for managing staff and practices that focus on young person's choices. Many of these practices are connected.

Some organisational practices were intentionally flexible to facilitate initiative by the young person and worker in how they organised the support relationship, such as policies about contact or staff rostering. In some cases this flexibility was to their advantage, because it enabled them to adjust to the preferences of each. However, initiative relies on confidence, capacity and power within a relationship to voice preferences, be heard and act on them. Not all young people or workers were interested or able to exercise this initiative in ways that supported their mutual recognition.

Policies that operated as guidelines or a principles framework to encourage initiative by the young person and worker opened up possibilities for the pair, such as some examples of support planning practices. However, often support workers controlled whether they acted on these opportunities, reacting to young people's input into the decisions, for example meeting out of work hours. Initiative relied on well-trained, supervised, supported workers to take up any policy guidance or resist constraints. It was not clear whether and how the organisations addressed the misrecognition if workers were not comfortable to act in this way.

The findings demonstrated that the pairs or a member of the pair sometimes resisted organisational requirements, evidenced in the way they challenged, worked around or negotiated these. Their approach depended somewhat on the rigidity of the practices and the capacity of the members of the pair. Often passive resistance by finding and using gaps in organisational practices were effective strategies to maintain the relationship and foster conditions for interpersonal recognition. At other times young people and support workers capitulated to the constraints by not acting, reacting or speaking up, because the requirements were too rigid or they did not have the capacity to challenge them.

Generally the organisations tolerated or even encouraged resistance by, for example overlooking pairs working outside the formal practices or occasionally changing the practice. This reaction often centred on practices that enabled young

people and support workers to work together more productively towards the young person's own identified preferences, potentially fostering conditions for mutual recognition.

The power to respond to constraining organisational practices generally lay with the worker rather than the young person. This was evident in examples of workers making decisions to comply, resist or work around constraints, such as organising support in the community away from the organisation's site. Some young people were also able to overtly or subtly exert their agency and resist constraints associated with organisational requirements but they were exceptions. Examples were choosing activities that meant they had time with their preferred worker, such as making choices about programs in which to participate so that they would encounter or avoid the worker; choosing to protect themselves from further distress from yet another staff departure by not engaging deeply with the worker in the first place.

Some explanations for the imbalance between the power of young people and workers to exercise initiative or resist organisational constraints were structural. Formal practice levers such as planning and complaints procedures are not easily accessible for young people. Policies are formal, intimidating and sometimes unknown, and access to external advice and advocacy relies on knowledge of where and what to do. Young people described complaining only if the conditions were so bad that they would risk upsetting the people they relied on. This reluctance to resist was also the case for some support workers.

The above findings highlighting the interplay between organisationally mediated recognition and interpersonal recognition were evident to a greater or lesser extent in all four mediators – the support sites, applying policies, managing staff and practices to focus on the young person's support. They reveal a conflict between organisational and interpersonal imperatives, particularly when the practices do not enable the pairs to exercise initiative or resist the constraints. It seems that organisational practices that facilitated initiative within the pairs tended to be strongest in the last practice – the focus on the young person's support. This finding emphasises the advantage to pairs where the young person and worker are able and willing to exercise that initiative.

If young people and workers are to exercise initiative and resistance in their relationship and within the conditions of the organisation, they need the confidence to do so. Organisational practices to facilitate that confidence are vital for most people, who do not have the experience, power or knowledge to engage in these practices. Such organisational practices include training, supervision, reflective practice, communities of practice, co-production, feedback mechanisms, imaginative use of internal space and local community spaces (P. Fisher & Byrne, 2012). Introducing conditions that seek and encourage proactive engagement from young people and workers is challenging for organisations because it requires acknowledgement that the interests of the young people, workers and organisation are not always compatible. Organisations that intentionally encourage initiative and resistance open themselves to critical input. These concepts are consistent with

continuous improvement through co-production, but they are challenging for organisations under short-term external pressures to their sustainability, especially in the transition to individualised funding under the NDIS.

The findings about practices to manage staff are limited because the research was only conducted with pairs where staff were employed by organisations, rather than any direct employment by young people or their families. This organisational context may explain why these practices seemed to be the ones where the young people had least opportunity to exercise initiative and resistance, since the practices restricted their direct involvement in organising both with whom and when they worked with someone. The study was conducted in six diverse organisations and further research could explore the four themes identified in this study in other organisations. At the conclusion of this study these issues were discussed in workshops with participants, staff and managers of organisations across the field. The workshops were a knowledge exchange opportunity for participants to critically discuss the themes to translate into action within their organisations. As the policy context changes in the move towards greater individualisation of support, it was valuable to learn from each other about how to work with the expectations of people with disabilities and support workers within the constraints of the policy context.

Limitations of the study

A limitation of the study was that as participants were recruited through organisations, no direct employment relationships between the person with disabilities and worker were included.

Conclusion

The impact of organisationally mediated conditions on interpersonal recognition between young people and paid support workers was evident from this empirical analysis. It extends the conceptual literature on interpersonal recognition that proposes that institutional norms mediate the way relationships, including paid support relationships are experienced. Ikäheimo (2015) describes this as mediated horizontal recognition. Organisational practices that encouraged initiative in decisions within the pair facilitated opportunities for their preferences to be expressed and heard by each other and acted on in the paid support relationship and sometimes also contributed to forming an informal relationship. Notably, it seemed that often when the pair resisted organisational constraints, the organisation condoned or encouraged the resistance. These organisational practices help to highlight the possibilities and constraints on the interpersonal relationships of the young people and support workers.

These implications mean that organisations that employ support workers must continue to address ambiguities in roles that potentially impact on relationships so as to routinely foster the conditions for interpersonal recognition, respond to

misrecognition between the young people and workers and encourage struggle within the relationships. In this way workers and young people are encouraged to explore new ways of being within paid relationships, which has impact on their other relationships and their identity more generally.

These implications are important in the context of the international move towards individualised funding, such as the NDIS, where the flexible means to organise supports encourage initiative and resistance. It intimates that organisations that provide support through an employee relationship must acknowledge the likely rigid constraints in their policies and seek to address them with practices that facilitate initiative in support relationships and encourage resistance. In contrast, direct funding or self-management is more likely to have a starting advantage with the direct control of the organisational mediators by the person and their social supports. Both direct funding and organisations with employees will continue to be organisationally mediated by the macro-level policy context (K. Fisher et al., 2019). These national policies must also then seek to remove constraints and facilitate the conditions for recognition between people receiving and providing support.

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References

Banks, S. (2016). 'Knowing me, knowing you': Disability support worker as emotional mediator? *Sexualities*, *19*(5–6), 659–676.

Blonk, L., Huijben, T., Bredewold, F., & Tonkens, E. (2019). Balancing care and work: A case study of recognition in a social enterprise. *Disability & Society*, *35*(6), 972–992.

Carey, G., Malbon, E., Olney, S., & Reeders, D. (2018). The personalisation agenda: The case of the Australian National Disability Insurance Scheme. *International Review of Sociology*, *28*(1), 20–34.

Clark, J. (2012). Using diamond ranking as visual cues to engage young people in the research process. *Qualitative Research Journal*, 12(2), 222–237.

David, C., & West, R. (2017). NDIS self-management approaches: Opportunities for choice and control or an Uber-style wild west? *Australian Journal of Social Issues*, 52(4), 331–346.

Fisher, K., Gendera, S., Graham, A., Johnson, K., Robinson, S., & Neale, K. (2019). Disability and support relationships: What role does policy play? *Australian Journal of Public Administration*, 78(1), 37–55.

Fisher, P., & Byrne, V. (2012). Identity, emotion and the internal goods of practice: A study of learning disability professionals. *Sociology of Health and Illness*, 34, 79–94.

Graham, A., Powell, M., & Truscott, J. (2016). Facilitating student wellbeing: Relationships do matter. *Educational Research*, 58(4), 366–383.

Graham, A., Truscott, J., Simmons, C., Anderson, D., & Thomas, N. (2018). Exploring student participation across different arenas of school life. *British Educational Research Journal*, 44(6), 1029–1046.

Guldvik, I., Christensen K., & Larsson, M. (2014). Towards solidarity: Working relations in personal assistance. *Scandinavian Journal of Disability Research*, 16(supp1), 48–61.

Hastings, R. (2010). Support staff working in intellectual disability services: The importance of relationships and positive experiences. *Journal of Intellectual and Developmental Disability*, 35, 207–210.

Honneth, A. (1995). *The struggle for recognition: The moral grammar of social conflicts* (pp. 323–347). Polity Press.

Honneth, A. (2001). Recognition or redistribution? Changing perspectives on the moral order of society. *Theory, Culture & Society*, 18(2–3), 43–55.

Honneth, A. (2004). Recognition and justice: Outline of a plural theory of justice. *Acta Sociologica*, 47(4), 351–364. https://doi.org/10.1177/0001699304048668

Honneth, A. (2007). Recognition as ideology. In B. van den Brink & D. Owen (Eds.), *Recognition and power: Axel Honneth and the tradition of critical social theory*. Cambridge University Press.

Ikäheimo, H. (2015). Conceptualizing causes for lack of recognition: Capacities, costs and understanding. *Studies in Social and Political Thought*, 25(2), 25–42.

Jurkowski, J. M. (2008) Photovoice as a participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46(1), 1–11.

Lutz., D., Fisher, K. R., & Robinson, S. (2015) Sharing the focus: Engaging with support workers to include people with communication needs in research. *British Journal of Learning Disabilities*, 44(2), 138–145. https://doi.org/10.1111/bld.12126

Macdonald, F., & Charlesworth, S. (2016). Cash for care under the NDIS: Shaping care workers' working conditions? *Journal of Industrial Relations*, 58(5), 627–646.

Marquis, R., & Jackson, R. (2000). Quality of life and quality of service relationships: Experiences of people with disabilities. *Disability and Society*, 15(3), 411–425.

Meltzer, A., & Davy, L. (2019). Opportunities to enhance relational wellbeing through the National Disability Insurance Scheme: Implications from research on relationships and a content analysis of NDIS documentation. *Australian Journal of Public Administration*, 78(2), 37–55. https://doi.org/10.1111/1467-8500.12373

Neale, J. (2016). Iterative categorization (IC): A systematic technique for analysing qualitative data. *Addiction*, 111(6), 1096–1106.

Niemi, P. (2015). The professional form of recognition in social work. *Studies in Social and Political Thought*, 25, 174–190.

Palmer, M., & Scott, A. (2018). Emotion work, interdependence and 'care' in relationships between physically disabled people and disability support workers. *New Zealand Sociology*, 33(1), 53–74.

Prain, M., McVilly, K., & Ramcharan, P. (2012). Interacting with adults with congenital deafblindness: The experiences of disability support workers. *Journal of Intellectual and Developmental Disability*, 37(1), 27–34.

Robinson, S., Blaxland, M., Fisher, K. R., Johnson, K., Kuang, C., Graham, A., & Neale, K. (2020). Recognition in relationships between young people with cognitive disabilities and support workers, *Children and Youth Services Review*, 116. https://doi.org/10.1016/j.childyouth.2020.105177

Robinson, S., Graham, A., Fisher, K. R., Neale, K., Davy, L., & Johnson, K. (2020). Understanding paid support relationships: Possibilities for mutual recognition between young people with disability and their support workers. *Disability & Society*. https://doi.org/10.1080/09687599.2020.1794797

Romer, L. T., & Walker, P. (2013). Offering person-centered supports on a daily basis: An initial appreciative inquiry into the relationship between personal assistants and those seeking support. *Research and Practice for Persons with Severe Disabilities*, 38(3), 186–195.

Rossiter, R., Scott, R., & Walton, C.G. (2014). Key attributes of therapeutic communication', In T. Levett-Jones (Ed.), *Critical Conversations for Patient Safety: An Essential Guide for Health Professionals*. Pearson, Sydney.

Shakespeare, T., Stöckl, A., & Porter, T. (2018). Metaphors to work by: The meaning of personal assistance in England. *International Journal of Care and Caring*, 2(2), 165–179.

Skär, L., & Tamm, M. (2001). My assistant and I: Disabled children's and adolescents' roles and relationships to their assistants. *Disability and Society*, 16(7), 917–931.

United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006) https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Williams, V., Ponting, L., Ford, K., & Rudge, P. (2009). 'A bit of common ground': Personalisation and the use of shared knowledge in interactions between people with learning disabilities and their personal assistants. *Discourse Studies*, 11(5), 607–624.