





Understanding paid support relationships: possibilities for mutual recognition between young people with disability and their support workers

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ABSTRACT

The quality of paid relationships is key for effective support, yet little is known about how people receiving and providing support understand and experience the relationship. This paper reports on recent research that explored the role of relationships with paid support workers in strengthening the rights and well-being of young people with cognitive disability in Australia. The research used photo-rich participatory methods with 42 pairs of young people and their support workers and drew on Honneth's recognition theory to specifically explore experiences of being valued, respected and cared about in their work together. The findings point to the importance of these connected aspects of recognition in paid support relationships, highlighting both the presence and absence of these, as well as experiences of misrecognition. The implications of recognition for strengthening support need close consideration in an international context characterised by personalisation of support, resource constraints and inquiries into poor practice.

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Points of interest

- Relationships are key to good quality support. We wanted to know whether and how paid support relationships between young people with cognitive disability and support workers in Australia contribute to feeling valued, respected and cared about.

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- Young people felt valued when the worker noticed what they did and found ways to help them achieve what they wanted to do. They felt respected when they could make decisions about choices and control over their lives. They felt cared about when they felt personal warmth, they were listened to, they felt their views mattered and they trusted each other.
- When young people felt harmed, they felt it deeply. The worker often did not intend to cause harm with their words or actions. The careless harm sometimes was from unequal power in the relationship. The inequality sometimes took away the voice of the young person. Sometimes the support worker also felt like their voice could not be heard.
- The research is important because how we feel about being with another person is key to how we know who we are. It develops the self-esteem, self-respect and self-confidence of the young person and the support worker. Knowing this matters for improving the quality of personal support.

Introduction

Support workers and other paid staff play an important role in the lives of many people with cognitive disability, including young people (Hastings 2010). The relationships young people share with their support workers can be pivotal in supporting their independence, wellbeing and social connectedness (Skär and Tam 2001; Mason et al. 2013). Support workers can be instrumental in fostering broader and more diverse social networks by facilitating access to people, places and activities in the community (Romer and Walker 2013). This potential to facilitate other relationships can be important given that many young people with cognitive disability experience loneliness and social isolation at higher rates than their non-disabled peers (Salmon 2013), can find it difficult to establish long-term friendships, and may encounter multiple forms of ableism and stigma in their social relationships (Mason et al. 2013). Moreover, while there is a strong literature on concepts such as staff stress and burnout, the effects on support workers of their relationships with people with disability¹ remain under-explored. In this paper, we draw on recent empirical research to address the research question: Which aspects of paid relationships contribute to recognition and ongoing identity formation of young people with cognitive disability and their support workers?

Focus on mutual experience

Previous studies have tended to focus on the perspectives of either support workers or older adults with disability who receive support (Hastings 2010;

Bigby and Wiesel 2015). Very little research has focused on the experiences of young people or on the mutual experience of working together in a support relationship. Considering relationships from the perspectives of both young people and support staff can generate valuable insights into how they work together, interact with one another, and build and sustain mutually rewarding relationships. In turn, such knowledge can inform how capacity building and organisational and governmental policy might more effectively strengthen quality in support provision into the future.

Relationships in a changing policy context

There has been very little research to date on the perspectives of young people or adults with cognitive disability in the current Australian context and the introduction of the National Disability Insurance Scheme (NDIS) heightens the urgency for further research into the role of support relationships. NDIS is a population-wide scheme, anticipated to provide 10 per cent of people with disability with individual funding packages, and 90 per cent receiving support through mainstream services. People and organisations are navigating a new disability support system focused on facilitating choice and control through individual funding and personalised planning, part of an international paradigm shift towards personalisation and the marketisation of disability services (Carey et al. 2018; Muir and Salignac 2017). There is no one model of support provision under the NDIS; indeed, the scheme encourages people with disability to exercise choice over the way they wish to be supported, and by whom.

Developing the capacity to build mutually rewarding and enabling support relationships has become more critical in this changing policy environment, to help ensure young people do not miss out on the potential created by increased funding, flexibility and choice. Support work involves intimacies, emotions, and social interactions that are not purely task related or instrumental (Shakespeare, Stöckl, and Porter 2018; Kelly 2011). Indeed, when paid relationships are instrumentally approached, without opportunities for both parties to influence how they relate to one another and the character of their work together, social engagement and relationship building for young people can be diminished (Hall 2010; Skär and Tam 2001). Likewise, support workers can feel undervalued (Shakespeare, Stöckl, and Porter 2018) or excessively restricted by organisational rules denying people emotionally rewarding authentic engagement with each other (Fisher and Byrne 2012). At worst, young people with cognitive disability may experience abuse and neglect by support workers (Robinson and Graham 2020; Jones et al. 2017) and support workers may report economic dependency and exploitation (Shakespeare, Porter, and Stöckl 2017).

While the more intangible or ‘affective’ elements of the working relationship are determining factors in both support worker and support recipient satisfaction with services, they are often overlooked in policy and organisational procedures concerning disability support. Job descriptions and policies tend to focus on the tasks workers perform rather than the relationships they form (Prain, McVilly, and Ramcharan 2012; Marquis and Jackson 2000), and attention to relationships is rarely part of support worker training programs (van Oorsouw, Embregts, and Bosman 2013). Hence, there have been calls for support policy and systems to foreground the importance of relationships more strongly (Christensen 2012; O’Brien 2013; Marquis and Jackson 2000).

This paper analyses empirical data from a recent study that used recognition theory (Honneth 1995, 2001, 2004) to gain a deeper understanding of the interpersonal relationships between young people with cognitive disability and their support workers. Recognition theory contributed to a conceptual and analytical framing of this mixed method inquiry to ensure it moved beyond the rehabilitative and service oriented approaches commonly applied in disability research (Yeung and Towers 2014, Cummins 2005), to access the rich experience of young people with cognitive disability and their support workers.

Why recognition theory?

Located within critical theory, the work of recognition scholars (Taylor 1995; Honneth 1995; Fraser 1995) is largely interested in self-actualisation, social equality and social justice. In this sense, ‘recognition’ is closely aligned with the rights of disempowered and minority groups – in this case young people with cognitive disability. Danermark and Gellerstedt (2004) examined the relevance of interpersonal and redistributive recognition theories to disability studies. While this paper was underpinned by such interests, it specifically set out to explore *relationships* between young people with cognitive disability and support workers. Hence, it drew predominantly on Axel Honneth’s (1995, 2001, 2004) theorising of recognition since his work is grounded in an understanding that interpersonal relations are inextricably linked with developing and maintaining the identity of a person or group and in constructing normative criteria for a just society (Turtiainen 2012). Honneth stresses the relevance of *inter-subjectivity* in the formulation of one’s sense of identity, which emerges from three modes of recognition which he identifies as love, rights and solidarity. ‘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 a person’s

particular traits and abilities, and the distinctive contribution these bring to a community (Honneth 1995).

Struggle

Inherent in the concept of recognition is the notion that achieving recognition requires an element of 'struggle' (Honneth 1995). In addition to the 'struggle' for recognition as a social group, people also encounter 'struggle' for self-actualisation as they come to understand their human dignity, worth and rightful place in the world (their evolving identity as human persons). Hence, Honneth's three modes of recognition, in turn, are bound up with positive *self-relations* (self-esteem, self-respect and self-confidence), with such self-relations being viewed as integral to identity formation. Identity formation and the pursuit of autonomy and agency are critical to leading a fulfilling and purposeful life, with the current policy context geared towards facilitating this. Struggle, in this context, therefore casts power relations as potentially productive, not only in the development and maintenance of a person's identity but also in creating a more just society.

How has Honneth been adapted for this research?

In earlier research exploring relationships between young people and adults (Thomas et al. 2016; Graham, Powell, and Truscott 2016), the language of these three modes of recognition was adapted to practice settings - love, rights and solidarity were translated with and by young people as 'cared for', 'respected,' and 'valued'. This framing was adapted to 'cared about' so as to not reinforce historically and ideologically loaded notions of care in the context of disability support. 'Caring about' in this project was experienced and described through feeling and/or being known and liked; on attentive noticing (such as providing opportunities that show me you know I am capable of something); and mutuality or a sense of reciprocity. Respect in this project is embedded in its theoretical genesis in 'rights'. It refers to the ways people speak to and about each other; actions and words that demonstrate respect; being heard and responded to; and a sense of being entitled to be treated with dignity. Valuing as applied in this project is about shared concern, interest or value; and the ways in which the pairs created the conditions for someone to contribute. Valuing is evidenced in the ways people recognise and respond to the particular contributions, gifts and roles played by individuals.

Honneth does not presume the three modes are experienced in equal measure. Instead, these may be present or absent to varying degrees in any relationship. The three modes provide a *multi-dimensional* view of

recognition and are often inextricably linked such that one act may simultaneously reflect being cared about, respected and/or valued.

Misrecognition

Any experience of misrecognition, which Honneth describes in terms of humiliation, hurt and degradation, damages the identity of the person (Honneth 1995; Taylor 1995). Misrecognition prevents people from participating in social life (Fraser 2001) which is a particularly damaging experience for many young people with disability. Distinguishing where both recognition *and* misrecognition are possible and present in relationships is therefore critical. In this research, experiences of misrecognition included exclusion, insult or degradation; feelings like shame, humiliation or anger; neglecting or ignoring and having low expectations.

Honneth's recognition theory has been used to understand paid relationships in children's lives (Graham, Powell, and Truscott 2016) and in social work contexts (Rossiter 2014). Building on this earlier work, the current study constructs young people with disability as rights bearers. In paid relationships in disability support, support professions are premised on care and respect, and paid support is often structured around the setting and achievement of goals. However, less focus has been placed on the role of valuing in these relationships. For the purposes of this study, then, Honneth's three modes of recognition were perceived as holding considerable potential for understanding these paid relationships. Given Honneth's theorising of recognition is largely focussed on close personal relations, the presence and absence of being cared about, respected and valued may play out differently in paid support relationships.

Not all young people with disability have a support worker, and the paid relationship is not central to the lives of all the young people who have one. Where they do have this relationship, at best it can contribute to wellbeing for both people involved, as well as to the formation of other relationships and wider social connections for the young person. At worst, the support relationship becomes a site of misrecognition that causes harm.

Research process

The study recruited a diverse sample, including young men and women with cognitive impairments and a range of support needs, paired with a support worker of their choice. Service organisations in six locations that supported young people with cognitive impairments (including intellectual disability, autism and brain injury) were invited into the project over twelve months in 2016 and 2017. The organisations all provided day support to people with disability with a variety of needs, and three also provided accommodation

support. Three organisations were located in urban areas, and three in rural towns. Three of the six organisations had more than one hundred clients in the service site, and three had fewer than one hundred. The organisations facilitated the introductions to young people aged 25 years and under. If the young people volunteered to participate, they were asked to nominate and invite a support worker of their choice to form a pair. Where this pairing process was not successful several young people agreed to service managers matching them with a support worker they knew. It was not always completely clear which was a pairing initiated by the young person and which was matched by service managers.

Participants

The relationships of the 42 participant pairs were diverse. The 23 young women and 19 young men were aged between 18 and 25 years. Their level of cognitive impairment varied widely across the group, from some who held driving licences to a few who needed support with all activities of daily living and communication. Several also had other physical and psychosocial disabilities. The workers were 28 women and 14 men, aged from early 20s to early 60s and ranging in experience from just a few months through to over 20 years. Most people were paired with workers of the same gender. Most pairs had worked together for less than three years, although 15% were together more than five years. Most young people received support in a group (65%) and 29% had individual support. Typically, the young people were involved in structured programs focused on life skills, community participation, transition to work, work experience and respite. Activities included classroom style learning, independent living skills in the home and community, one-to-one social activities, and group activities at the service or in public spaces. Many pairs were in contact with each other outside their paid time together, usually between programs at their service.

Data collection

Each set of data for a pair included interviews conducted at the outset of the project, social maps, photo-research and repeat interviews. An initial joint interview mapped their shared understanding of the people they knew, places they went, and things they did together. In individual interviews immediately following, participants reflected on the maps and shared perspectives about working together. Pairs were then supported to take photos about their time together over 3 months. In the second set of joint and individual interviews, each selected their preferred photos, following photovoice methods (Overmars-Marx, Thomese, and Moonen 2018), where the process of

taking, selecting, agreeing and discussing photos elicits data about the relationship. Individual interviews with the pairs were conducted first to capture any distinctions between young people and workers' choices of images, and reasons for this. Participants explained the significance of the photos they took and ranked them using the diamond ranking method (Clark 2012). In joint interviews the pairs were asked to rank the photos together, according to what they conveyed about their working relationship. The researchers were able to observe the ways that power and control were at work in the relationships during these processes. Interviews ranged in length from 15 to 90 min. Researcher observations were systematically recorded in journals. Some young people did not use any or much verbal language, so the combined data sources with activities and visual images were important to capture their experience of the relationship.

Data analysis

All data was coded for shared meaning using NVIVO software. Thematic analysis of the data was conducted by coding the data according to the recognition framework and emergent themes. This approach helped to ensure alignment between the theoretical framework and data, while also allowing for emergent themes to provide critique of the framework. The next stage of the analysis was conducted using iterative categorisation (Neale 2016), with standardised procedures that facilitated rigour in the inclusive analysis of key themes with the project's two researchers with cognitive disability and with the young people's advisory group.

Ethical considerations

Ethical approval for the research was provided through the lead university, Southern Cross University, Australia [ECN-16-022]. Given the potential power imbalances in the pairs and sensitivities which meant that participation may have longer term implications on the relationships, close attention was also needed to ethics in practice as the research unfolded (Powell, Graham, and Truscott 2016). For example, some support workers were more guarded with information about their lives, which affected the sense of mutuality in some of the pairs. Some young people described tenuous arrangements with support workers, which gave rise to uncertainty about the relationship, such as the duration or consistency of working together. In turn, this affected young people's motivation to invest in building a relationship where they felt this would likely end or abruptly change. Some young people's impairment affected the emotions they expressed about the relationship. Through the adapted project methods, almost all young people and support workers

provided detailed perspectives on the ways they experienced their working relationships, particularly through their photographic choices and descriptions of the meanings behind them. One support worker withdrew from the research, leaving one young person unable to continue in the project. One other support worker left during the project, and that young person partnered with another worker. Names used in the results are pseudonyms and the participants engaged in a scaffolded consent process to give permission for a selection of their photos to be used in an exhibition, a book and in specific academic publications. Evidence of the findings are supported by relevant quotes and photos. The title on the photos are in the young person's words. The photo captions describe the content of the photo.

Results

The results are presented according to the primary themes generated in the analysis. Given that Honneth's recognition theory closely informed the analytic framework, the results below report the core interests of the working relationships around feeling valued, feeling respected and feeling cared about; and the intersections between the modes.

How the pairs experienced their working relationships

The analysis generated insights into the ways in which relationships between young people and workers influenced conditions for interpersonal recognition. Using Honneth's modes of recognition as an analytical framework illuminated a distinctive characteristic in the support relationships. Honneth argues that the experience of love (being cared about) must be experienced before we can experience respect or valuing (Martineau et al. 2012). However, as the data below highlights, the pairs prioritised goal achievement with young people (being valued), and this established a particular dynamic for the relationships that is explored later in the paper. The weight of the data linked to the three modes resulted in the foregrounding of valuing, before considering respect and caring about, and the intersections between the modes, as presented below.

Feeling valued

Many young people and support workers expressed valuing of each other and themselves through appreciation of each other's roles within the relationship and acknowledging the particular talents or hard work each put into achieving their goals working together. Some pairs articulated their felt sense of value from their work together, particularly noticeable in the pairs who described pride in their mutual achievements. Alongside this, attentive



Figure 1. This is me and Linda on air together. Linda was very nervous at the start, but I helped her through it.

noticing of personal qualities such as good humour or careful listening were associated by the pairs with care and respect for each other. For example, one young man reflected on a series of photos taken by his support worker of him acting in his drama class, saying that he particularly liked them because people were watching him and he felt acknowledged. His support worker said he took a back seat in this activity, offering encouragement and taking pleasure from the young person's enjoyment. This highlights the possibility that valuing within the support relationship may also promote the broader goal of valuing by peers.

Many support workers expressed pride in the value of their work assisting the young person to achieve their goals.

I don't have to put in the effort that I do ... I can follow the job description and only do a quarter of what I do, but it's not me ... [I] just want to make a difference. It's extremely fulfilling, I wouldn't do it if it wasn't. (Eva, support worker)

Several young people were proud of the ways they helped their support worker to try new things, demonstrating their value to each other, illustrated by the pair below, who chose this photo and caption about reversed support roles. In the caption, the young person describes how he took a lead role in supporting the worker practically and emotionally in their work together (Figure 1).

Valuing contributions made by young people

Young people talked about feeling valued when they made a contribution. These were active roles within the disability services, such as demonstrating their musical skills in leading activities with other participants, representing

their service through advocacy work and on committees, cleaning or maintaining property like buses, or assisting with programs. Support workers often laid the groundwork for these roles, creating spaces for leadership by young people within groups and making clear their appreciation of the benefits of the young person's contribution.

Cathy (YP): My role would have been like a manager role, just to ...

Beverly (SW): You facilitated groups.

Cathy: Yes, facilitated like to make sure everyone's seated and everyone's listening ...

Beverly: Then you talked about your life experience ...

Cathy: Yes.

Beverly: And how people worked with you and the type of work that you did.

Cathy: Yes.

Young people also felt valued for their work and their contributions in the community, describing them in ways that indicated these enhanced their sense of esteem. For example, one woman spoke about how much she enjoyed regular swimming with her support worker, and captioned a photo of herself in the pool 'I'm a strong woman at swimming!'. Support workers organised opportunities for young people based on their skills and aspirations, with the aim of building their capabilities and confidence. These included employment, community gardening, exhibiting art, and busking. These young people felt valued that their preferences were acted upon. Support workers felt that without their initiative, these opportunities would not have been considered.

Several pairs also reflected on the time each contributed to the relationship as being important in feeling valued. Less tangible contributions included the qualities they liked in each other. Young people talked about enjoying a good sense of humour, patience and energy in their paired workers, and support workers expressed admiration for qualities in the young person such as their determined focus, or persistence learning a new task.

Effect of goal-focused relationships on valuing

Where the support relationship was more transactional, the pairs knew each other less well. This may have limited opportunities for them to experience valuing of each other's distinctive contributions. Some paid limited attention to the effort made in the relationship by the other member, giving little regard to effects on their partner of devaluing or not acknowledging their qualities and contribution.

He just sits around, just looks at his phone. That's what he does. But he still has to watch me. (Jason, young person)

Support workers generally accepted lack of valuing from the young person in the context of their role supporting someone with cognitive impairment, but on occasion some found it trying to be unacknowledged for significant effort and they noticed when this changed.

You don't get a lot of thanks in this job, not that [young people] don't appreciate it, but it's the last thing, I think, they think of ... As soon as he got his [driver] licence, he came up and he was really happy and he shook my hand and said thanks for your help ... It was a nice meaningful part of the job. (Marie, support worker)

The purpose of the support relationship framed the way that both were focused on working towards the goals of the young person. Because of the dominance of planning and goal setting, where young people did not have a strong goal orientation, opportunities for experiencing being valued were more muted. A few support workers only focused on their contribution as professionals and their impact on the young person, and expressed little acknowledgement of the contributions of the young person to the relationship.

Feeling respected

While there were tensions within some relationships, experiences of feeling respected, as well as absence of respect, were evident in the data.

Choice and control

Feeling respected was evidenced in the tacit and explicit ways the relationship promoted the agency of the young person. In particular, many young people said they felt respected when their voice was heard, when they experienced choice, and had influence over time and activities with their support worker. Some young people felt confident in expressing their preferences, knew how to ask for things to be changed when they were unhappy, and experienced a sense that change was possible. For example, one young woman conveyed pride in her success in organising work experience by sharing a photo of herself doing her job. She was particularly pleased to have organised this herself after several efforts by her support worker had been met with refusals.

The pairs spoke about times when they felt a sense of mutual respect, emphasising qualities that they appreciated in each other, such as listening and being listened to; not bossing each other around; paying attention to each other's choices; and being considerate of each other's time. This had the effect of building a sense of confidence and authority for the young person, in particular.

I am pretty good at helping people problem solve. Yeah, we help each other to solve problems. Which is really what you're meant to do in life. (Jennifer, young person)

We've known each other about two and a half years. We've well and truly worked out how not to push each other's buttons, and how to, yeah, just look at our faces and know if something's up ... (Chrissy, support worker)

Often the pairs spoke about the right to make choices, but felt the right was constrained in significant ways that undermined the agency of the young people. They both felt that choice was inhibited in their organisations and more widely in the community, affecting the degree to which young people could actively make their own decisions and the choices staff had working with them. For example, staff rostering affected the ways that some pairs were able to work together.

Dylan (YP): They says it's just changed, because that's how the boss said.

Researcher: So this is just a new rule, and you have to put up with it?

Dylan: Yeah.

Marie (SW): We've all had to put up with it, didn't we?

Several support workers described their role as being to minimise the constraints. They described their efforts to build opportunities for young people to carry out their choices. The opportunities were often scaffolded over time. Examples included writing a role in a play that allowed a young person to express their non-binary identity, lobbying management for increased choice-making for lunch options, and planning sole-trader support to provide more flexible support arrangements. In some cases, young people were aware of efforts by their support worker in helping them maintain choice and control.

Respect within power structures

The ways many young people discussed respect was circumscribed within a power dynamic where a worker was more articulate and in a dominant position. Sometimes the young person intentionally leveraged this power difference.

I was thinking of asking Damian if he could [intervene to help my suggestions be heard] - my suggestions, they're kind of awesome, but some of the guys turn around and say "yuck." (Julian, young person)

Understanding the fluid power dynamics within the support relationship was highlighted in one pair who were also in a music band together. The young person described a difference between the roles, saying that in the band, everyone had the same goal, whereas in the support relationship, he expected his worker to lead and help.

Young people often described respecting their support worker in terms of working within the rules or being adaptable to changes, even when these bothered the young person. Some young people described not showing respect for their support worker when they deliberately disrupted group activities or were reluctant to do agreed tasks. The support workers rarely perceived this as disrespect, and instead understood it as the young person's resistance to constraints on choice.

Support workers spoke of having shared goals with the young person, but also about ways that they felt they showed respect to the young person by prioritising the preferences of the young person over their own wherever possible, setting realistic expectations with them about their support, and finding additional support if needed. Some workers said that when young people were dissatisfied with their support, they used opportunities to reflect with them about their right to choose and the potential consequences, within the organisational context of their support relationships:

We just have that respect for each other and do hit it off with each other and that doesn't seem to have any problems. [However], I don't think anything could be changed [we could achieve anything] if we have to keep within the goals that we've got to keep with. (Sonya, support worker)

Absence of respect

At times, respect was not evident. In most instances, this was when either the young person or support worker was careless about the way their actions affected the other. Examples included non-attentive support, assumptions that the young person was not affected by changes to support, or disregard of the support worker's actions in organising support. Generally, it seemed to be an absence of the expression of respect, not active ill treatment or intention to cause distress. However, young people, in particular, often articulated this experience as one of *misrecognition* through the use of words such as 'not happy', 'shocked', 'confused', 'hurt' (feelings) or 'not told'. Generally, the lack of respect was shown by being unattentive to the ways actions or words could be interpreted (rather than intentional disrespect), but its impact could be damaging. As a result, some support relationships revealed significant power imbalances and silences (and silencings).

One young woman spoke about a time when they were travelling in the car with a group of people, and she was irritating the group. The support worker pulled over, told her to get out, and locked her out of the car. In their joint interview, the support worker related the story as a joke. Later, the young person spoke separately about this:

Researcher: It looked like it bothered you a bit.

Billie (YP): Yeah.

Researcher: When you got back in the car, how was it? Did you just pretend you were cool with it?

Billie: I was like, "You fucking bastard."

Researcher: What did he say?

Billie: They just all cracked up laughing.

Tensions were more evident when the pairs reflected on respect within their relationship, than valuing and caring about. Most young people responded passively to experiences of *disrespect*, possibly assuming that they had little influence over expectations, service conditions or program requirements. Support workers' reflections on feeling disrespect focused on not being valued; or institutional disrespect within the sector or organisation.

Feeling cared about

The experience of feeling cared about appeared to be implicitly linked to a concern for each other's wellbeing as persons, beyond the focus of the specific working relationship or the activity they were engaged in. The pairs mainly conveyed this in terms of a sense of feeling secure in mutual knowledge of each other and comfort and friendliness within their interactions. At times there was confusion and tension in the ways people cared about each other, particularly around friendliness and friendship and when care was not a reciprocal experience.

Caring about as necessary for knowing each other

Concern for each other's wellbeing extended beyond nominal roles. Young people primarily conveyed experiences of being cared about in terms of feeling safe and free to express their needs to their support worker, and having their perspectives taken seriously. In part, this centred on particular goals of their service programs, but also extended to feeling that the worker cared about their wellbeing. Some young people also spoke confidently about reciprocating this kind of care in their working relationship, particularly by sharing jokes together, but also in encouraging their worker, as evidenced in this photo where one pair shared a running joke they had about their hair-styles ([Figure 2](#)).

Young people often sought opportunities to be alone with their support worker, to share parts of their daily lives, for emotional support when needed, and for reassurance when not feeling supported by others. They described ways their support worker built their confidence, helped them regain calm when they were anxious or to negotiate things that triggered distress. For example, one young man described the physical discomfort and anxiety he experienced when support workers drove too fast in the van. He



Figure 2. The three mop heads. We have lots of laughs together.

appreciated that his support worker always booked the more comfortable van and took care to drive slowly.

One young person reflected on what he enjoyed about his support worker's company, focusing particularly on the regular catch-up conversation they had over morning tea and how they negotiated arrangements, such as who was bringing the food for that week, and who was ensuring that the tea bags were stocked up. He valued the way that his worker helped him relax into conversations based on shared history:

Greg (YP): I think because [we have] a good time together.

Researcher: Do you have a few laughs?

Greg: Yeah. But not too far.

Support workers discussed their efforts to deepen contact with the young person, such as spending time chatting about what was important to them and seeking opportunities outside rostered time together to check on their wellbeing. Knowing the young person well was, for some support workers, key to being responsive to their preferences.

I can be her friend, but I have to remember that I'm a professional. I'm in this for a reason, and that is to make sure that she progresses. (Patty, support worker)

... every day I always check in and make sure he's all right. I always say hi and make sure he's okay. If I see that he's not right, I'll pull him aside and ask him if he wants to have a chat. (Charlotte, support worker)

Tensions in caring about linked to confusion about friendship

Caring about each other was at times contested. While the pairs spoke of similarly about warmth and *friendliness*, there were distinctions in how they approached notions of *friendship*. In some instances, the feelings about friendship were not mutual – young people often expressed views about friendship where support workers spoke about friendliness, limited by what they perceived to be appropriate within professional boundaries. The distinction was often not clear to young people, compounded by words used by many of the support workers and young people to describe the ways they felt about each other, such as ‘love’, ‘friends’, and ‘friendship’.

Several of the young people described their relationship with their support workers as a friendship, identifying it as such because they felt mutual care for each other.

She made me look good; be safe around her ... and probably she’s a good friend.
(Kylie, young person)

A few young people identified the distinction, saying that they could be friendly with workers, but this was different to being friends.

Beverly’s sort of a work friend ... It doesn’t mean that I can’t go out with her, and have some time with her, but it’s just a bit hard at the moment with me doing my things. She’s tagging after me, and trying to support me in that way. (Jennifer, young person)

A few of the pairs spent time together outside their work socialising and on social media. A few support workers invited young people to family outings, having coffee on days off and attending birthday parties. These support workers articulated the difference between their work and personal friendship in terms of power relations, the ways that their activities were negotiated, and how they communicated together outside work. However, very few young people discussed ways in which they negotiated the conditions of personal friendship with support workers.

Tensions between professional and personal positions were frequent, exemplified by situations that potentially involved workers in pushing policy boundaries, for example, by sharing elements of their personal lives – such as phone numbers, Facebook contacts or time together outside work time. Such dynamics caused disquiet for some support workers, given their concerns that such actions may not be consistent with their professional role or the organisational policy.

She feels very safe and trusts me if she needs to talk about something. I probably do talk in a teacher-y sort of way, because I’m not a girlfriend and I’m not a mother. I suppose the teacher thing is probably the only role that I could ...

Researcher: Yet, she did say best friend.

... I know that we are friends. Look, I do say that too ... when they go, "Are you my best friend?" I go, "My god, yeah, of course, I'm your best friend. I will always be your best friend." Maybe she does see me as her best friend and I've not realised that interaction that we do have is maybe the only girly, type friend. (Patty, support worker)

Caring for or caring about?

An absence of caring about was also evident in some of the relationships. The distinction between recognitive caring *about* and merely caring *for* was evident where care by the support worker inhibited the young person's opportunities to try new things, develop social relationships with others or build independent skills. For example, young people spoke about feeling disregarded when they expressed preferences for different ways to approach group decisions. In other instances, some workers spoke in front of young people with little regard for how they might perceive comments about the burdens of their job, and others prioritised the company of other workers over the young people. A few support workers described feeling resentful about having to complete tasks that they felt young people should have addressed, particularly housework. In the research activities, several people protested or retreated into silence when their preferences were overlooked or choices dismissed in their pair. When this occurred, both young people and support workers said they felt ignored, that their input was minimised and their opinions were not important. Such findings highlight a degree of interpersonal struggle in the to-and-fro of seeking a more intimate relationship of friendship and a paid professional relationship. At times this was aggravated by confusing signals from some support workers.

Intersections between the modes

For the purpose of analysis, the modes of recognition were separated in the analytical framework, as reported above. Nevertheless, these modes often presented as interwoven. In these intersections, dynamics around mutuality, trust and power were evident.

In the joint interviews, support workers generally took pains to promote the agency of the young person. In providing many examples of the ways that young people cared about them and other young people who used the services, they showed their esteem for the young person, respect for their (sometimes) developing skills and appreciation of their personal qualities. For example, one pair discussed a photo from their research, taken of the young person with a celebrity at an event where the young person was working as a DJ:

Researcher: If you think of all the gigs that you've done as [a] DJ, was that one of the best ones?

Daniel (YP): I couldn't [ask] for more

Michael (SW): It's always good to capture [him] in his natural habitat of DJing, and with someone of some form of national significance. A couple of celebrities together.

Several pairs expressed their mutual support. For example, one pair spoke at length about how they had supported each other through the recent death of someone close to them both, sharing music and memories that brought them both comfort. Stimulated by discussing the photos they took for the project, many of the pairs spoke about the pride they had in their relationship, the value they placed on it and their appreciation of the opportunity to spend time together. These examples highlight the nuanced ways the pairs conveyed concern for each other beyond professional requirements. Embedded within such interactions was a mutual sense of respect for the rights of young people and valuing of their contributions.

Discussion and conclusion

In using Honneth's recognition theory as a theoretical and analytical frame for this inquiry, we aimed to identify possibilities whereby support relationships may provide the conditions for mutual recognition to occur. This is important because recognition is a vital human need (Taylor 1995). Common to most social and political notions of interpersonal recognition is the shift from an atomistic to an intersubjective, dialogical understanding of the person. Relationships are key to this. Because our identity is shaped precisely through our relations to others, our being recognised by them, feelings of self-worth, self-respect and self-esteem are possible only if we are positively recognised for who we are (Honneth 1995; Rossiter 2014).

The findings reported above demonstrate the potential recognition theory has for analysing and understanding the ways that paid relationships between young people and support workers contribute to identity formation (self-confidence, self-respect and self-esteem) through such recognition (Rossiter 2014). The three modes were often conveyed as *interwoven*, but to understand how these influenced the working relationships, we analysed them separately. By doing so, we were able to more clearly identify the explicit ways pairs worked together in their relationships, and the degree to which each mode is present or interacting with other modes of recognition. In the process, we also uncovered instances of misrecognition, absence of recognition and institutionally mediated recognition. We identified the interconnected nature of the modes, and that the paid context of the relationships means that, for some pairs, interactions will be characterised by some dynamics more than others.

The importance of valuing to the pairs in the relationships is a significant finding from this study. The pairs acknowledged measurable contributions and personal qualities they brought to the relationships. When they had invested time and interpersonal resources in their relationships, they identified tacit qualities in each other such as kindness, resourcefulness and good humour. For people who for myriad reasons (personal, systemic and structural) do not have specific skills, the privileging of achievement may risk overlooking qualities that can sustain quality and mutual satisfaction in support relationships – such as trust, care and respect.

Interpersonal respect between the pairs was heavily mediated by the institutional context of their relationships. This reality often constrained opportunities for the young person to control decisions about their support. Young people's sense of agency was dominated by a shared view that they needed to ask permission for change. Many support workers tried to mitigate the effects of limited access to choice, in many cases working to scaffold opportunities which promoted options. This mutual struggle for recognition was striking in mediating the lack of access of young people to the means to negotiate control over their service use and wider participation. However, when respect was absent or muted within the pairs, the power imbalances in the relationships meant that young people were more likely to experience misrecognition, feeling silenced and disregarded.

The analysis also enabled us to see the effect of unevenness in the modes of recognition. This was particularly evident where we identified explicit examples of caring about, but limited acknowledgement of a person's agency or the personal qualities and contribution they made to the interpersonal relationship. In these situations, we identified interpersonal warmth and mutual regard, but not necessarily the conditions from which people develop their self-esteem, self-respect, and self-confidence. As flagged earlier, Honneth argues that the experience of love (cared about) must be experienced before we can experience respect or valuing (Matineau et al. 2012). If this is so, it helps to explain tensions in relationships when young people may look for a closer relationship than is possible in this context, the worker resists or is ambivalent towards this, struggle ensues, and the other experiences of recognition are impacted.

Previous research has called for support policy and systems to foreground the importance of relationships more strongly in the provision of support to people with disability (Christensen 2012; O'Brien 2013; Marquis and Jackson 2000), acknowledging the gaps in addressing the intangible or affective elements of support (Shakespeare, Stöckl, and Porter 2018; van Oorsouw, Embregts, and Bosman 2013). This focus is important both for the quality of the paid relationship and the potential to support the formation and maintenance of *other* social relationships. Hence, this study points to the need for

closer attention to the ways in which power is played out in support relationships and the possibilities for this to be potentially productive. This is also important in terms of acknowledging agency and promoting decision-making by and with people with cognitive impairments. Our findings about tensions negotiating friendship and friendliness are also important in the context of difficulties for some people with disability in the social world, given the potential facilitative significance of the support relationship for people who are socially isolated (Salmon 2013; Romer and Walker 2013).

Institutionally mediated constraints have been recognised as organisational rules denying emotionally rewarding authentic engagement with clients (Fisher and Byrne 2012), and system- and structural-level abuse (Fisher et al. 2018; Robinson 2015). Interpersonal relationships are built on unequal ground – aspirations of people with disability are mediated by support workers; access to resources is determined outside the interpersonal relationship; and when the pair need to negotiate tensions, young people are reliant on the quality of the support for successful resolution. This is consistent with other recent work using recognition theory which points to the fragility of recognition in these conditions (Blonk et al. 2020).

In focusing on *mutual* experience, this study provides new empirical evidence about the impact of relationships of support on young people and support workers, and theorises about the potential of interpersonal recognition for identity development in this context. We do not intend to overstate the significance of this relationship in the lives of the people involved, and acknowledge that these are relationships with a purpose – to facilitate purposeful, meaningful lives for people with disability (Hastings 2010; Bigby and Wiesel 2015).

Our findings showed that the likelihood of this facilitative work happening in purposeful ways was highest when the pairs had invested in their interpersonal relationships – particularly when there was valuing of the young person's unique contribution, combined with mutual caring about one another and an embodied respect for human rights. Connection built from relationship. However, this relationship-building role is likely a challenge for support workers to integrate as a core part of their work, helping ensure they support people with disability to develop and sustain relationships in a range of community spaces. Without this, there is a considerable risk of continuing or even worsening the pain and loss that people with disability feel as they invest in relationships with workers who inevitably move on – underlining the potentially damaging effects of institutional and personal misrecognition.

The findings provide considerable insight into the possibilities, constraints and tensions in the relationships between young people with disability and support workers. This, in turn, influences experiences of mutual recognition

and any benefits that might evolve from this, including for identity formation. It is important to note here, however, a number of limitations in our approach to this research. While there were sustained (repeat) interviews with the pairs, this was not sufficient to gain a definitive insight into the everyday routine aspects of the support relationships and how this might influence the recognition and identity formation of the young people and workers. Indeed, this was not our intention since it is not possible to really know relationships from the outside. Further, not all young people selected their 'partner' worker as intended in the study design, so the nature of the relationship was quite different across the sample. The pairs took up the photographic methods with varying levels of enthusiasm, which led to some variability in data available for analysis from each pair. In analysing the data through a lens of recognition theory, we acknowledge that many issues remain unexplored. Other papers from this project explore some of these, such as the institutional mediation of the interpersonal relationships and the effects of space and place on the working relationships. One potential risk in applying Honneth's interpersonal recognition theory as it has been in this study, is that in prioritising the relationship between the pair, and the ways in which this did or didn't create the conditions for mutual recognition to occur, the approach overlooks the substantive role of the support worker in facilitating other relationships and interactions (Shakespeare and Watson 2018; van Oorsouw, Embregts, and Bosman 2013). The analysis avoids this risk by arguing that the substantive support role is unlikely to be fulfilled if the relationship itself is not characterised by some experience of mutual recognition, as evidenced through the modes discussed above.

The findings of this study nevertheless affirm the role that paid relationships potentially play in promoting the inclusion, participation and autonomy of young people with cognitive disability. Using recognition theory to analyse the views and experiences of young people with cognitive disability and support workers about their relationships provides useful insight into *how* these relationships are circumscribed and enacted within the context of paid support – including through the mutual experience of being valued, respected and cared about. Given its pivotal place in the disability policy landscape, further attention needs to be given to the nature of the support relationship between people with disability and support workers. That said, this study was completed with people using disability support services. Further research with people with cognitive impairment who are self-managing their support would be valuable, to see whether and how the nature of their support relationships are shifting with greater control over support.

Disability support organisations need to foster understanding of the potential significance of recognition. Careful consideration needs to be given to significant relationships and how the experience of mutual recognition

shapes the identity of people with disability and the professional self-concept of support workers. This may take the form of capability building for people with disability, professional development for support workers, or organisational capacity building. For example, organisations need policies, management and training of support workers to support their understanding that caring is part of their job, not inconsistent with it; but that caring about isn't sufficient if in the absence of respect or valuing, it is experienced as misrecognition.

One of the benefits of an inclusive research approach to this theoretically informed study has been that we developed ways to help people talk about their relationships, concretising abstract ideas and making them accessible (Neale et al. 2017). As the project moves into the knowledge exchange phase, this might enhance support work by helping people pinpoint how they want to strengthen their working relationships, build the skills to name ongoing tensions, and identify and address misrecognition.

Relationships are likely to be a central focus of large-scale inquiries and initiatives across the globe – the Australian Royal Commission into Abuse of People with Disability and the National Disability Insurance Scheme being just two examples. In the context of large-scale change, we need to keep underlining the importance of relationships, and how these work, in contributing something better at an individual level for both people with disability and the workers who support them.

Note

1. In keeping with preferred terminology in Australia, this paper uses the terminology person/people with disability

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