“Well hang on, that’s sort of not right”: Family and staff perspectives on 'cultures of respect' in supported accommodation services for people with intellectual disability

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Executive Summary

Background

The high levels of abuse and poor quality of care in supported accommodation services for people with intellectual disability is a significant and ongoing concern in the State of Victoria, Australia and in countries such as the UK. The culture of services is increasingly recognised as significantly influencing service quality and outcomes. Mainstream approaches to abuse prevention suggest the importance of ‘bystanders’ in shaping service cultures, and condoning abuse. However, little is known about how bystanders in supported accommodation services - staff and families of service users—understand or translate concepts, such as rights, dignity and respect, which are fundamental to good quality services and abuse prevention, into practice. A greater understanding of their perspectives may provide insights into strategies for building and reinforcing cultures of respect.

Aims and Method

This study explored: 1) How families of adults with intellectual disability who use supported accommodation services and staff understand the concepts of rights, respect, dignity and abuse, and what they look like in practice; and 2) What families and staff thought might strengthen a ‘culture of respect’ in supported accommodation services. In-depth interviews were conducted with fifteen people, predominantly parents, from eleven families with a relative with intellectual disability living in supported accommodation. Thirty-five staff from three disability service organisations participated in five separate focus groups. Both groups of participants were asked about their understanding of rights, respect and dignity, what these looked like in practice and to comment on six vignettes that depicted staff interactions with a service user. An inductive analysis was used to identify key themes in the data.

Findings

Family members were strong advocates for their relative in supported accommodation. Most recalled vividly incidents of abuse or disrespectful behavior. Staff and family members shared quite similar views about key concepts, and both groups suggested the cumulative effect of small every day actions and interactions on service quality and as indicators of potential problems. Rich and detailed examples, both positive and negative, of the elements
of respectful practice or practice that upheld service users dignity, identified by both staff and families, are included in the report.

*Elements of respectful practice identified were:*

1) Regarding each individual as their own person, ‘it’s his life’ – recognising each person’s right to be oneself and control their own life regardless of what other people wanted.

2) Enabling support, ‘supporting them to achieve’ - recognising and providing the right type and amount of support to enable a person to control their own life.

3) Sensitivity through interactions and language, ‘the way we speak’ – recognising that every person with intellectual disability is an emotional being, and reflecting this consistently in language and social interactions.

4) Taking time to find out, ‘so you’ve really got to read’- staff having more than a superficial impression of each person with intellectual disability, and being enabled by the organisation to have sufficient time or resources to review information about the person. This meant even casual staff having awareness of key information about person’s health and support needs.

5) Navigating complexity, ‘none of these things are clear-cut’ – recognising the necessity for and making complex judgments to deal with tensions between respecting choice and safeguarding a person’s wellbeing or dignity.

6) Staff-service-family collaboration, ‘there’s discussion about what I think’ – recognition and due regard to the knowledge, views and role that families play in the lives of people with intellectual disability. Families described a deep sense of alienation and disempowerment that characterised their relationships with staff at various levels in disability service organisations. As a consequence many felt unwelcome and excluded from consultation and decision making about their relatives’ life. This sixth element of respect was identified only by families, and as it was largely missing from services they described it primarily in the negative.

Practices that upheld dignity were associated with more personal aspects of a person’s appearance and privacy, and had two elements:

1) Social acceptability, ‘looking great’- enabling a person to look and behave in socially acceptable ways in order to counter discriminatory attitudes, boost their self-esteem and avoid being embarrassed.

2) Privacy, ‘just knock’ – respecting the right to personal space, and sensitive private personal care.
Perceptions of potential abuse vignettes

Staff were unanimous that all six vignettes presented to them, portrayed quite serious abuse of service users’ rights. Almost a quarter of family members were equivocal in making firm judgments about the first four vignettes that showed the inappropriate use of power or disrespectful practice resulting in subtle abuse of service user rights. However, all families thought that the last two vignettes portrayed examples of sexual and physical abuse.

What would make a difference?

As well as strengthening skills of staff to put into practice the five element of respectful practice identified by both families and staff, families emphasised the need for greater collaboration between services and families of service users (the sixth element of respectful practice that only they had identified). Other ways to improve the quality of practice suggested by both families and staff were to strengthen front line and organisational leadership, and increase willingness to report poor practice or incidents of abuse. Both groups of participants however, held reservations about staffs’ capacity to speak out about poor practice, and families felt they were actively discouraged from speaking about service users other than their relative.

Staff referred to three inter-related strategies they used to guide their practice and ensure it was respectful: 1) using themselves as the point of reference for how they treated people; 2) remembering they were guest in people’s homes, and; 3) leaving their values at home. Based on previous research and philosophical writing about the ethics of care the first and third of these may be problematic and require some reframing.

Discussion

The practice elements identified in this study that foster respect and dignity reflect many aspects of established person-centred practice approaches, particularly Person-Centred Active Support (Mansell & Beadle-Brown, 2013). There are few guides to practice aimed at front line staff that illustrate the translation of high level principles into expected actions for staff. One of the challenges for practice leaders and others involved in staff training and supervision is finding easy heuristics or reference points for staff to guide their practice that are not overly procedural. The detailed examples of both good and poor practice for each of the elements of respect and dignity in this study provide powerful illustrations of the translation of abstract concepts into practice.
The findings reflect research evidence about the contribution of organisational processes and strong practice leadership that provides support to staff, in the form of supervision, modeling and constant vigilance of their practice. Both families and staff referred to the importance of coherent values throughout the organisation, and the importance of investing in strong frontline practice leadership as a key strategy to develop cultures of respect in supported accommodation services.

Staff and families did not fully appreciate each other’s perspectives about the complexity of supporting people with intellectual disability to exercise choice and control. This together with the relative absence of strengths based language among some families, and their blunt reference to limitations of capacity, potentially gives the impression that some families are out of step with current policy directions and human rights imperatives. However, families have had few opportunities to share their ideas and dilemmas or grapple constructively with new service directions. This is a significant gap in the disability support system that should be addressed.

Relationships between family members and staff were more likely to be characterised by conflict rather than collaboration. From the experiences of families, the sixth element of respectful practice; staff-service-family collaboration, was largely absent from services. This important element had also been identified by the Disability Services Commissioner (2014), from analysis of complaints received, which led to the development of guidelines for the basis of engagement between services and families. Building constructive engagement, greater respect for each other and more collaborative relationships between services and families of services uses will build and strengthen cultures of respect in supported accommodation services.

The findings of this study give insights into the potentially negative impact for service users who have no one other than staff who is concerned with their wellbeing or who monitors the service they receive. Families of service users are well placed to be more active bystanders in respect of all service users in the supported accommodation services they visit, but at present are actively discouraged by staff from speaking out about poor practice they observe in respect of services users other than their relative.
Recommendations

1. A guide to respectful practice for front line staff that includes some easy points of reference be developed from the data collected as part of this study.

2. Investing in structures and skilled staff that enable strong frontline practice leadership should be a key strategy in developing culture of respect in supported accommodation service. As one aspect of this, disability service providers should be challenged to think about more creative and effective ways of ensuring all staff, including casuals have sufficient knowledge about service users to enable support to be tailored to their individual needs.

3. Opportunities should be available to family members of service users for mutual support and to explore further and discuss the core concepts in current disability policy and the shifts that have occurred in approaches, language and values over the past 50 years.

4. A consortium of academic researchers, the Office of the Disability Services Commissioner and disability support organisations should seek funding to implement and evaluate the guidelines developed by the Commissioner as the basis for families and services working together. As part of this project different approaches to enabling staff and family members to build common understandings of each other’s perspectives, develop a common language and hone their negotiation and problem solving, should also be piloted.

5. All service providers should develop a clearly documented approach to working with families of service users that is reflected in organisational processes and structures. This would provide a framework for families of service users and service providers to individually negotiate, document and regularly review their expectations of each other.

6. Addressing the absence of social relationships in the lives of service users who have no involved family members, through specific network building strategies, should be a priority and regarded as a key preventative strategy to tackling abuse and disrespectful practice.

7. It should be everyone’s responsibility to identify violence, abuse and neglect, and by implication, the small and subtle actions by staff in services that can culminate in major incidents. The role of families of services users as more active bystanders in supported accommodation services and mechanisms to enable families to report poor practice with confidence that some follow-up will occur should be explored further, and guidelines for families developed to parallel the Office of the Public Advocate’s, interagency guidelines for addressing violence, neglect and abuse (2013).
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Background

Rights, respect and dignity for people with disabilities are key principles in state, national and international disability and human rights policies. For example, the Victorian Disability Act states that people with disabilities have the right of “respect for their human worth and dignity as individuals” and to “live free from abuse, neglect and exploitation” (Victorian Disability Act (2006, 5, 2, a, b). The culture of supported accommodation services and the practice of support staff are pivotal to realising these rights each and every day for people with intellectual disability who live in services; as the UK Quality Care Commission (2014) suggests ‘poor care, neglect and abuse go together’.

Various approaches are in place to translate policy or legislative principles into organisational processes and expected staff practice, and to monitor the quality of services. Staff practice is guided by the policies and procedures in documents such as the Residential Services Practice Manual which is regularly published and updated by the Department of Human Services (2012) as well as in-house practice frameworks developed by non-government services (see for example, Clement & Bigby, 2010). Although many of these remain at the level of high level principles they do reflect an underlying body of knowledge about supporting people with intellectual disability to communicate, be engaged, socially included, and to exercise choice and control. They promote the use of person centred practice approaches such as Active Support and Positive Behaviour Support. The Victorian Disability Standards translate the principles that underpin the Disability Services Act into expected processes and practices of organisations delivering services. Accompanying these, as a guide to implementation, are indicators of the types of evidence required to demonstrate compliance with the standards. Internal quality assurance processes, and in Victoria, regular external audits, are the primary means of monitoring the quality of organisational processes and practices. Statutory independent bodies such as the Office of the Disability Services Commissioner, the Community Visitor Program and the Office of the Public Advocate provide avenues for complaint and alternative ways of monitoring staff and organisational practices, implementation of legislative principles, and thus of safe-guarding people with disability from abuse.

Despite the existence of rights based disability policies in Victoria, and
internationally, research as well as enquiries by statutory bodies and media reports demonstrate that people with intellectual disability experience abuse at higher rates than the general population and other groups of people with a disability (Horner-Johnson & Drum, 2006; Cambridge, 2007). They show too that staff and service cultures are not always respectful and some staff devalue people with a disability and regard them as ‘other’ (Office of Public Advocate, 2011; White et al., 2002; Carter, 2000; Robinson & Chenoweth, 2011; Bigby et al., in press; Flynn & Citarella, 2013). The abuse exposed at Winterbourne View in the UK by the Panorama program in 2011 resulted in prosecution of staff and closure of the specialist facility for people with intellectual disability and challenging behaviour. It was a potent reminder that disrespectful or cultures of abuse can occur in smaller congregated settings as well as the large institutions of the past, and the serious impact of this on people’s wellbeing (Flynn & Citarella, 2013; Plomin, 2013).

Almost coinciding with the exposure of abuse at Winterbourne View in 2011 reports from the Victorian Ombudsman (2011), Office of the Public Advocate (2011) and the Disability Services Commissioner (2012) drew attention to the significant number of incidents of abuse observed in supported accommodation services in Victoria. Serious concerns were raised about the capacity of the current disability service system to “adequately protect the rights of people with a disability to be free from abuse and protected from harm” (Disability Services Commission, 2012). Indeed since this study commenced in 2012, further serious infringements in Victoria, of the rights and dignity of residents in supported accommodation services have been exposed by the media (Baker & McKenzie, 2012, 2013).

In parallel with public exposure of serious cases of abuse, in depth qualitative research identified five dimensions of culture in underperforming group homes in Victoria (Bigby et al., 2012). These were; 1) a misalignment with the organisation’s espoused values where staff often said “we’re not going to do it that way”; 2) a sense of otherness, as staff saw the service users as “not like us”; 3) staff felt their job was to be doing things for people, in other words, “we look after them” rather than enabling them; 4) working practices that were clearly staff-centered, “we get it done so we can sit down and take a break”; and 5) resistance to change, “yes, but….”. The impact of these cultural dimensions on service users was a lack of engagement, community participation, choice, and personhood. In some respects comparisons could be drawn between the culture in these services and that of institutions.
A follow up study that examined the culture of ‘good’ group homes demonstrated the potential for cultures of respect in group homes. This study found staff regarded service users positively, as members of a common but diverse humanity (Bigby et al, in press). They recognised both sameness and difference of people with intellectual disability. Rather than attaching negative value to difference they paid significant positive attention to it in their everyday work. The study drew attention to the explicit and continuing attention required to sustain a culture in which staff positively regarded service users in their everyday practices and turned abstract values into concrete realities. Recruitment and induction processes regulated staff entry, ensuring newer staff saw good practice being modeled. Staff were recruited for their values which were thought to be harder to shape than their skills. Formal policy about language, and processes such as peer monitoring and strong practice leadership reinforced the translation of values into expected actions. The qualitative data in this study illustrated what an abstract concept like positive regard, which is closely related to dignity and respect, looked like in practice.

Response to abuse in disability services in Australia, until recently, has been reactive to individual incidents, blaming the ‘bad apple’ staff member or the victim’s lack of capacity to safeguard themselves (Page et al., 2002). In Australia, unlike the UK and Canada, mainstream violence and abuse prevention frameworks have not been widely used to understand and develop strategies to tackle abuse in supported accommodation services. Such frameworks adopt a systemic approach identifying factors in the social ecology of services contributing to abuse and the type of change needed in systems. For example, the Vic Health violence and abuse prevention framework suggests the need for change from ‘cultures of abuse’ to ‘cultures of respect’ (VicHealth, 2007). This requires an understanding of attitudes and behaviours of people in the immediate environment who are the potential bystanders or perpetrators of abuse and of the wider socio-cultural attitudes and structures that condone or perpetuate abuse. It leads to strategies aimed at different elements of the social system to effect change.

In the context of supported accommodation services, a socio-ecological perspective to abuse prevention suggests the need to consider the various groups of people who interact with residents, and whose actions both shape and have the potential to change the culture in group homes. Those who interact directly with supported accommodation residents will include managers, frontline supervisors and staff, family members, and other residents. Little is known about the way family members understand rights, respect and dignity, what constitutes
abuse, their knowledge about it or confidence in the avenues open to them to take action if they are worried about the staff practices they observe. Likewise, little is known about the way staff apply principles such as respect and dignity to their practice or the interactions they perceive as disrespectful or potentially abusive. Understanding how staff and family members understand and apply these principles and their perceptions of abuse can provide insights into strategies for building and reinforcing a culture of respect in supported accommodation services.

The aim of this study was to explore the way families of people with intellectual disability who live in supported accommodation services, and staff, as potential bystanders and perpetrators of abuse understand rights, respect, dignity and abuse. This understanding can be used to inform the development of strategies to effect change to elements in the social ecology of services that allow disrespectful or abusive cultures to develop and be sustained. In particular how family members might be empowered to be effective bystanders, able to recognise and take action about poor practice, abusive and disrespectful behaviour in supported accommodation services in respect of all residents. The research questions were: 1) How do families of people with intellectual disability who use supported accommodation services and staff understand the concepts of rights, respect, dignity and abuse of rights, and how do they perceive these as being put into practice; and 2) What do families and staff think might strengthen a ‘culture of respect’ in supported accommodation services?

**Approach and Methods**

A qualitative methodology, designed to elicit how participants understood the key concepts of rights, respect, dignity, and abuse was used. The study sits within a social constructionist research paradigm as its purpose was to generate a conceptual rendering from data (Crotty, 1998) rather than simply being descriptive. The inclusion of a person with intellectual disability as part of the research team for some parts of the data collection strengthened the study’s rigor and helped to ensure a perspectives of a person with intellectual disability was included in interview discussions (Ramcharan, Grant & Flynn, 2004). Data was collected using in depth semi structured interviews and focus groups which included use of structured vignettes based on examples of abuse from prior studies. Data were analysed inductively using the principles of grounded theory (Charmaz, 2014). Ethical approval was obtained from the Human Research Ethics Committee of LaTrobe University. All participants gave written informed consent to participate in the study.
Participants

Participants were drawn from two separate groups of people directly involved in supported accommodation services; frontline staff and supervisors and family members of residents with intellectual disability. Unlike some studies where staff and family members involved with a service user are recruited together, in this study each group was recruited quite separately. Consequently there was no direct connection between the staff and families involved in the study. Fifteen people from eleven families who had a relative with intellectual disability currently living or had lived in supported accommodation participated. All but 2 family members were parents of older adults and were ageing themselves. The exceptions were a sibling and his partner, closer in age to their relative with intellectual disability. Most of the people with intellectual disability had lived in supported accommodation between five and ten years.

Staff from three disability service organisations participated in five separate focus groups. In one of the larger organisations, separate focus groups were held for staff in three different regional groupings, and one focus group was held for staff in each of the other organisations. Staff were direct support workers, frontline managers or practice leaders without direct line management responsibilities. A total of thirty-five staff participated in the five groups.

Recruitment

Participants were recruited through the partners involved in the research proposal, Yooralla and the Disability Services Commissioner, and other disability services and peak bodies who advertised the study in newsletters and staff networks. The recruitment process was difficult and very slow as the study coincided with widespread media reporting on a sexual abuse case in a large disability organisation (McKenzie & Baker, 2012). After several months of limited success, during which only two families had volunteered a respondent-driven sampling method which is commonly used to recruit hidden or hard to reach populations was used (Salganik & Heckathorn, 2004). Family members who had volunteered were encouraged to invite other families known to them to participate. This approach resulted in increased numbers of family participants, but it may have skewed the sample towards families with similar characteristics. This is a limitation of the study and a common criticism of such chain-referral sampling approaches.
Data collection

Family members participated in a semi-structured interview that sought information about their involvement with supported accommodation services, their perspective on the concepts of rights, respect and dignity and what these looked like in practice for their relative with intellectual disability. In the latter part of the interview they were asked to comment on six vignettes that depicted staff interactions with a resident with intellectual disability in a supported accommodation service. This approach was used by Petitpierre et al., (2013) in a study about abuse of people with disabilities who suggested it to be a “useful tool for the exploration of sensitive topics” (p 198). The focus groups with staff followed a similar semi structured schedule to the interviews with family members, the first part sought their views about operationalising respect and dignity, and the second sought comments about the same six vignettes that portrayed disrespect and abuse. Interviews with families and the focus groups lasted between 60 and 90 minutes and were conducted by the second two authors.

Analysis

The interviews were digitally recorded and transcribed verbatim, and read and reread by the three members of the research team without intellectual disability. Initial line by line open coding was done by one team member using NVivo Version 10 software (QSR International, 2013). The codes were discussed and refined by the team using a constant comparative approach (Miles & Huberman, 1994) and then collapsed into categories. Further coding and refinement of these categories was undertaken by the lead author which led to the themes reported in the findings.

All identifying data about individuals and service delivery organisations has been de-identified and where necessary pseudonyms used. Generic terms such as house supervisor or front line manager have been used to replace organisation specific terms that might identify the organisations in which staff participants worked. Many respondents referred to the Department or DHS and unless their comments identified particular services or staff they have not been de-identified. To identify the origin of the family quotes, each participant was assigned a separate number followed by F. The names of the service providers have been de-identified and are represented as RB, AB, CD, EF and GH in the text.
Findings

A brief description about the role of families in the lives of their relative in supported accommodation is presented first. This is followed by the perspectives of family members about the meaning in practice of the key concepts of respect, dignity and abuse, and their views on what might make a difference and contribute to stronger cultures of respect. Unless explicitly stated the themes presented are those which were strong and consistent across all the families who participated in the study. The second part of the findings presents the perspectives of staff and compares these to those of families using a similar format and approach.

Importance of Families - “whenever something isn’t right, I will always advocate”

Family members cared deeply about their relative with intellectual disability and had enduring commitments to their wellbeing. As one parent said about her daughter, “we want to improve her life as much as possible” (9F). They held high expectations about the type of support that should be received. Many families were regular visitors to the supported accommodation service where their relative lived, and were in frequent contact with the frontline staff and the more senior managerial personnel in these services. As the following sections illustrate, all the families in the study recalled vividly situations where they had identified disrespectful attitudes and interactions, abuse, and problems with the quality of the service. One mother vividly expressed her frustrations with the poor quality of support in the house where her daughter lived and her constant fears for her safety, saying,

They’re regimented, they’re all shipped off to the bathroom, one after the other…the food’s all shoveled in their mouths…the staff are not even giving them one to one attention, they’ll be yacking with the other staff…the mindset was, ‘well I’m here to do a job, I’ll feed them, I’ll shower them, I’ll change their bums, I’ll shove them to bed, and that’s it, and my job’s done’…I want Cathy to go, I want her to die, and that sounds really awful but her life is crap, and I’m terrified, every time that phone rings, I’m thinking, ‘oh, shit, what now?’ because I thought she’d be safe in that house, they’re all trained, they’re supposed to know what they’re doing, but the lack of communication, the lack of feeling welcome, the lack of house meetings, just everything sort of put together…I hate to think what goes on sometimes when I’m not there, I really do, and not just her, the others too… I look at it like this they’re just treated like blobs, they’ve just got to be fed and changed (9F).
Families did not however, paint a consistently negative picture of the quality of supported accommodation. Rather their descriptions of incidents that had occurred to their relative suggested fluctuations over time, pointing to the tenuous nature of quality services. As one parent said,

That’s even harder when they’ve got staff who are leaving all the time, too, and you haven’t got a culture of consistency (7F).

One family in particular recounted the very poor service their son had received and the long struggle to change things. During the interview they spoke very positively about what they termed the new ‘A team’ staff, that had replaced the previous teams. Another parent spoke about the changes for the worse that had occurred in one service,

Up until 12 months ago…but probably in the last three years there’s been problems getting team leaders, reliable team leaders…they don’t tell you anything, there’s no information given by Garland House, occasionally they have a parent sort of thing, but nothing like they used to, they used to have parent information sessions, and all those sorts, they don’t do anything, nothing now (FL).

Most recalled instances where they had acted on what they saw as poor staff practice, abuse or neglect, and some of them recounted a long history of advocating on their relative’s behalf. As one family member said, “anything I wasn’t 100% happy with, I would try and discuss and hopefully get some strategies” (1F). Another said, “whenever something isn’t right, I will always advocate, for her, over and above what she’s able to do” (2F).

Some families, particularly the older parents, had invested significant time and emotional energy in advocating for their family member, and felt worn out by their efforts. For example one mother said,

We’re only fighting back for Jake, we’d rather be on a holiday somewhere far, far away, we don’t want to be doing this, we don’t at this time in our lives, we haven’t got that much time left, to waste it on this stuff (11F).

Another mother talked about the stress she experienced in advocating for better services for her son,

I was furious, I was like steam coming out my ears every day, and in the end I went up there…Well now, I have this very serious issue about alopecia where I’m looking at losing my hair through stress, and I would say that the Department [DHS] is responsible for that (6F).
Family Perspectives on Respect and Dignity – ‘every day, in a thousand subtle ways’

Families found it difficult to separate rights, respect and dignity from overarching ideas about the quality of support. As one family member said, “respect and dignity really sort of meld into one” (5F). Another said, “the words dignity, respect, and abuse need not to be just considered in their traditional concepts, but associated with the more subtle lack of consistent quality of life care services” (3F). They drew attention to the way everyday staff attitudes, interactions and behaviours translated these concepts into practice, “in every day, in a thousand subtle ways, this is happening all across the system” (5F). This parent and several others talked about the cumulative effect of many small actions that were often overshadowed by major incidents. She said,

Minor things don’t matter that much people don’t take notice of them, it’s because the police aren’t involved, and because there’s no blood. You know, DHS staff sort of think, well that’s all right, you know, what’s all the fuss about? But, put themselves in the position of them having that done to them, they wouldn’t like it (5F).

It seemed much easier for families to point to the negative and give examples of poor practices rather than positive examples of these concepts. As one parent said about respect,

It’s only when something happens that is adverse you go back and say, well why did that happen? And then you sort of …categorise it, that was lack of dignity or lack of respect shown to the resident (5F).

While respect and dignity were often considered together with ideas about rights and good practice, the analysis also suggested dignity was understood somewhat differently from respect. Using these 2 concepts as an organising frame, 6 elements of respect were identified and 2 of dignity. From the perspective of families the elements of respect that should be evident in staff practices were; 1) regarding each individual as their own person; 2) enabling support; 3) sensitivity through interactions and language; 4) taking time to find out, and; 5) navigating complexity, and; 6) staff-service-family collaboration. The 2 elements of dignity were social acceptability and privacy. These elements are discussed below with exemplar positive and negative staff practices.

Elements of Respect - Families

Regarding each individual as their own person - ‘it’s his life not ours’

Encapsulated in this element was regard for the person with intellectual disability as
an individual with the same expectation of rights and respect as other members of the community. One parent said, “it’s respecting someone’s individuality in that they are a human being at the end of the day” (7F). Another said, “I would expect the staff member to treat the resident like a normal person, the sort of rules that you can expect are no different than me talking to you and interacting with you” (5F). Implicit was the right to be treated as an adult and control one’s own life rather than it being controlled by others - the right to be oneself, regardless of what other people wanted. Several of the parents explained how difficult it was to put this dimension of respect into practice when someone continued to require support with basic needs into adulthood, or make decisions others might not agree with.

There’s a really fine line between getting him to do the things that are sensible and what he wants to do, and that’s a real issue with adult stuff…as an adult, you really have to step back and say what’s the most important things, is it important that he has to iron the clothes? To me it’s really important, but is it better that he goes out in un-ironed clothes or that he doesn’t go out, because he’s got un-ironed clothes? It’s better he goes out, and has exercise in un-ironed clothes. I think he should iron his clothes, but he doesn’t think he should iron his clothes, so, you know (6F).

It’s his life now not ours. Respecting the way they are and not trying to change them to comply with something that’s probably a little more easy for the staff or for the management or for a system. Just looking at that individually and just talking and listening to them, the exchange, the communication is really important to get, even though they’re nonverbal …just because they’re dependent on you, toileting, and feeding, and dressing, and things, doesn’t mean that they’re children…they are adults, and they need to be respected…have dignity as an adult and be allowed to make their own choices (8F).

The examples of poor practice given by families helped to illustrate what they thought respecting their relative’s right to control their everyday life meant. One parent for example talked about an incident where a new staff member overrode a long standing habit of her daughter of leaving her false teeth in overnight. She said,

Gillian came home, and she was really upset, because this person, who was the team leader in the house had insisted that she take her teeth out every night. She’s got false teeth in the front, now she’s never ever had to take them out, apart from a bit of
cleaning…I said, look, I’m really concerned. I spoke to Janet first, and Janet said to me, it’s an Occupational Health and Safety issue; she’s got to remove them at night (12F).

These extracts also hint that respecting the person as an individual meant their needs should be prioritised over those of staff which coincides with the tenet that services should be individualised and person centred rather than staff or group centred. This was not always the case as one family member used an interaction with a staff member to explain,

[the staff member said to me], if you think I’m going to take Kate out and not the others, you’ve got another thing coming. She said, I can’t take six of them out together, so none of them go. So I thought, hang on you’ve got six residents, take two, on Saturday, take two on Sunday, the following weekend take another two, then the Sunday…they all will get an outing, every fortnight, [but], no, if they can’t all go together, none of them go (9F).

As this comment from a mother talking about her son illustrated, this element of respect reflected a central principle of the disability movement – see the person not the disability,

He’s got a life experience, he’s got all those things that he’s done…Bob’s travelled, he’s been a volunteer, he’s been a worker, not for long, but he has been a worker, he’s done all those things, he’s moved interstate, he’s a harmonica player. When you talk about him but you could also say, he’s a man with Down Syndrome, he’s myopic, he doesn’t read and write, doesn’t walk very well, you know, all that stuff, but he’s got all that skill, now I would like to see workers understanding that there’s the full body there, the full person behind that and their whole life, and I reckon that’s where respect comes (6F).

Enabling support – ‘supporting them to achieve what they need to achieve’

Respecting people with intellectual disability for the person they are, meant recognising their right to control their own life as well as their need for support to do so which was greater than might be needed by other adults. This was captured succinctly by one family member, who framed respect as,

Well that would be respecting her, the abilities she does have…also respecting the lack of ability that she doesn’t have, and providing the support that’s needed (2F).

Respect was framed as providing the right amount and type of support to enable a person to make choice and be as independent as possible. This entailed not making assumptions on the
one hand that people could make choices alone and on the other hand just doing things for people. For example,

In many ways they are allowed to choose their clothes, are allowed to participate in the menu, are allowed to participate in what’s on television and, so it’s allowing them to participate, and sort of have rights, and exercise the rights…Yes and supported to do that, so that you present this to a person and you support them, and give them choices, and support them. What do they say, ‘you don’t do things for them, and you do things with them’ (5F).

There’s a key…he has to go and get the key to open [the cabinet], get the video that he has…so he comes down, he knows. Sometimes he’ll yell, from the front room, and they just say, ‘no, Sam, you have to come and get the key. So he’ll come down, and he gets the key, and he tells them he wants help, a little bit of help, to find where it is, and off they go, and help him do it. So you know, it’s him taking, some control (8F).

Another family talked about their son’s need for support to be engaged and the failure of staff to recognise and provide this,

James is a very complex puzzle piece, it’s very hard to tell whether James likes this, or likes that, or likes something else…James will just wander round the room doing absolutely nothing all day, unless you engage with him, so that is what the staff do not do. Quality of life care is where you engage with him…Guiding him to do things, making sure he’s got his slippers on, helping him put his slippers on, this sort of thing, helping him with his food, if he needs it, encouraging him to do this and that. He needs a little bit of supervision. He knows which to put on first, but if you hold up his trousers the right way, he can put them on, and he’ll pull them up, put t-shirt over, on his head, and he’ll pull it up, and then pull his arms through, he knows all that stuff, but he can’t do up buttons (3F).

Some of the examples families gave of staff practice that failed to take into account their relative’s need for support suggested that staff did not know the person well enough to be aware of the support they might need or have the skills to provide appropriate support,

To respect my sister…let’s start with the person centred planning. I walked into the room with this new team leader and on the wall she had stuck all these bits of paper, and I said to her, what are they up there for? And she said, that’s so we can write down what Gillian wants and what Gillian needs, everything for a person centred
plan, and I said, why, and she said, because, well we have to, and I said, but Gillian can’t read, so can you tell me why you need to put that up there, because it’s not going to help, that’s not respecting Gillian. She had no idea [about what she wanted in her plan], and she was sick, and she’s on medication, and all she could say is, I just want to be here with my friends, the rest was garbage (12F).

**Sensitivity through interactions and language - ‘don’t talk like that, he picks up on things’**

Families expected that language and social interaction would recognise that people with intellectual disability were emotional beings with feelings. One of the family members talked about the way she had learned from staff about being more respectful in the way she talked about her son now he was an adult rather than a child,

I think the house taught me a lot of things…not talking about certain things with the family and our friends. When perhaps he was younger, it was quite easy to say almost derogatory things about habits that Daryl has… Keith [my husband] might say something or I might say something about his dribbling and I feel now that that’s just not respectful especially when there are other people… I’ve said to Keith sometimes don’t talk like that about Daryl when he’s around people. Daryl knows, Daryl picks up on things you can see it in his face (8F).

Illustrating this point with a negative example, one family member said,

I’ve heard them yell out at this lady, if you don’t behave yourself you’ll be sent to your bedroom, so this to me is a most inappropriate interaction (11F).

Being sensitive to feelings included; not talking about a person in front of them and as if they were not there, not talking to a person as one might to an animal or a small child, not drawing attention to personal characteristics, shortcomings or discussing in public intimate details of personal needs. For example family members said,

The staff member will talk to me while Roger’s there, and by the time Roger comes on, he is so edgy, because he can’t hear what’s going on, and I said to him, Roger doesn’t like it when you’re talking about him on the phone (10F).

Another family member described a disrespectful interaction where the staff member had essentially talked to a middle aged man as if he were a child, and had fixed his appearance rather than giving him the chance to do this for himself. Talking about an interaction just as they were about to go out to the theatre she said,
I said [to Giles] you might need the jacket, because it could be a bit cool when we get back, and so the staff member said, oh, yes, right Giles, go and get your jacket. He came back with the most sleazy looking jacket, [she said] no, no, not that one, you wear that one to work. And with that, she physically pulled it off him, she didn’t wait for him…And then she says, Giles, I know you’ve got a bit of a ginger beard there, but I think you’ve got some of your dinner left on your face…So she comes back with a wipe, and wiped his face, and he’s 50 something years old, and why couldn’t she say, oh Giles, better just check the bathroom? (4F).

Taking time to find out - ‘read the care plan’

Families did not expect staff to know their relative as well as they did, but saw an element of respectful practice as having more than an ‘in the moment’, superficial impression of who the person was. This meant staff at least being aware of summaries such as ‘about me’ pages held on files that might sketch out information about issues of health and capacity. One family member thought that “casual workers should be able to have time to read a care plan, prior to their session” (7F). She went on to talk about a situation where a casual staff member was working alone with residents she had never met before, drawing attention to the way this element of respect stemmed from managerial as well as staff actions. She said,

The other day, when my husband turned up again, to take John back to the house, and there was a casual worker at the door in tears, because she’d been asked to be a worker at the house, but there was no one else there, she’d let herself in, all the guys were coming back from their day programs to the house, she had no time to read care plans, she’d never met any of them before, and there was no one else at the house, so she was just was in tears, and said to my husband, “Oh, you know, please stay with me”, so, he did, he stayed (7F).

Families felt that respect meant that staff should adopt a questioning stance towards what a person might say or their behavior. They expressed concern that simply taking things at face value posed risks to their relatives’ health and wellbeing. They said for example,

She presents well, and she says she can do something and stuff, [staff say], go well, off you go then, and it’s like you actually have to go read her notes, that says you must supervise her! But, you know, people especially casuals that come in and out, will just go, oh, off you go (1F).

I was there just recently, and there were two staff on…my sister had just come out of
hospital…she’d been discharged from the hospital the day before, [the staff] had no idea what she was supposed to do to help her. She’d had a gallstone out, and all they said was, but I just have to give her a Panadol if she needs it. My sister had wounds [from surgery and the staff member] had no idea (12F).

Another family member talked about the clear instructions in her daughter’s notes that due to a perforated ear drum she needed to use ear plugs when she showered, which were often ignored. She said,

Casuals get the blame for everything, which I think’s terribly unfair. But if they’re worded up properly, if the staff say, oh, okay, you can shower her, but she needs to have an ear plug in her left ear…I was ringing one of the staff, and he said, oh, it’s okay, I was just about to shower her, I said, well, don’t forget her earplug’, and he said, What? (9F).

Respect was not only being aware of information about a person but acting on it in a timely manner. Several families talked about staff who paid little heed to health related matters,

If somebody needs some sort of medical support, and they don’t get it, or they don’t get it on time and they go to the doctor and the doctor says, you should have this pathology test and the house supervisor says, yes, we’ll organise that”, and four months goes by, oh, yes, oh we must do that, you know, and the guy, and the person will be dead (5F).

And, so the resistance is always, well no, she’s independent, and the way they see it, oh, but we don’t care what the doctor says, the way we see her, she’s independent, she can shower herself, it’s like, but the doctor’s telling you that she’s got skin infections, and she’s been on antibiotics, because she’s not showering properly, and he wants you to supervise it, so, you’re going to do it, and then they go, oh, the staff feel uncomfortable, doing that. Well if they feel uncomfortable doing that, then they need to get another job (1F).

Navigating complexity – ‘this business of what is in Bob’s best interests’

Families pointed to the mediating factors that made respectful practice more complex than simply taking a person’s choices at face value. They alluded to the tensions that flowed from the impaired capacity of people with intellectual disability to understand the full picture or the consequences of choices or actions. One parent said for example,

Shelia presents better, or more, higher functioning than what she actually is…her
social quotient is a lot higher than her IQ, although she’s moderate, intellectual disability, but, because she presents so well, assumptions are made (2F).

Making their point that being respectful was not always straightforward; some families were very blunt about their relatives’ lack of capacity, using the analogy of their relative being a child. They said things like,

He can’t initiate anything. And he doesn’t even know how to ask… he’ll get this silly smirk on the face, and I say what do you want? And he can’t even tell you …. (12F).

It’s sort of like well, intellectually you’re dealing with somebody who is a baby...infant/toddler, you can’t expect too much (9F).

In being respectful they expected staff to ‘challenge’ choices of people with intellectual disability and exercise judgments about whether a choice was sufficiently ‘informed’. Respect meant seeking out alternatives perspectives (from family or written information about health or support needs), staff judging which of the sometimes competing perspectives held most weight, and then if necessary, which view of the persons’ ‘best interests’ should prevail. Many families suggested that staff did not do this well because of the constraints imposed by policies. Several even suggested that staff used the strong policy emphasis on service user choice as an excuse for poor practice. For example, if a resident chose to do nothing, then staff would not bother to provide opportunities or encouragement to participate as this comment from a family member highlights,

It’s very difficult...I think this question’s a very big issue, for the Disability movement, because, in our politically correct world we now have staff that can’t, or won’t, can’t probably because of the Occupational Health and Safety issue can’t direct people. They’re not skilled in leading people, there’s now this whole policy of, oh, you know, if you don’t want to go and do that, that’s all right, that’s your choice, and this business of the question of what is in Ben’s best interests, is it his best interests is to sit in front of the telly, all day, every day, and do nothing? (6F).

Several families gave examples of occurrences where they felt that their relatives’ tendency to acquiesce and staff failure to seek out other perspectives on the issue, meant staff had taken advantage of their relative who had been manipulated or pushed towards making decisions staff favored,

Roger got the best room, and then all of a sudden, we had a new management, and we had this lovely lady, she was really nice... and the next thing you know they turf him
out of his room, they didn’t tell me…Well, they said that Roger had a slip on the floor, and so they decided it was safer for him to be in this other room, because it had carpet outside the door. I don’t know why they moved him up, but they had their own reasons, but that wasn’t a valid reason; and they convinced him, he went quite happily, and he’s quite happy where he is, and of course, I freaked out, because the plan says, as discussed I must be advised of anything [that happens]…The “anything”, somehow or other didn’t fit, they thought it was still okay to do that without telling me (10F).

Okay, but the staff don’t want to go out on the bus…so they come out, and this is with ones who can talk…and they say to Johnny, “Oh, now, you don’t want to go out today, do you…and they say, “Oh, no”, because they’re out to please, staff, so that’s why they say no… because they seem to be like: “We want to please people” (3F).

Families saw that their views and deep knowledge of their relative should carry significant weight in staff judgments. They talked with anger and frustration about the detrimental outcomes that could flow from not consulting or respecting views of family. For example, one family member said,

They make assumptions, or they tell you what they’re going to do, they don’t ask you, and involve you in decision makings and things like that. They tell you and they think they’re advocating for the client, but there’s been reasons why Wanda’s care-plan’s supposed to be how it is…when they want to change things they just change it, and tell you after the fact, and as a result Wanda has ended up at the GP on long-term antibiotics, and different things like that, because of some of the decisions they’ve made, without sort of consulting (1F).

In a more extreme example, a parent talked about her perception that her daughter had been encouraged by staff, and subsequently an advocacy group to break off all ties with her. While others may have different perspectives, this family member perceived her daughter had been manipulated by staff. She said the staff had told her daughter,

You don’t need your mother, you can speak up for yourself… and there were serious issues there, duty of care issues, and then she, eventually she just shut me out, after eight and a half years of my complaints, they shut me down, through Shelia, they used Shelia, to shut me down…I knew she would fret…but I mean that was staff getting in her ear, every day, and supporting her, and saying: “No, you’re an independent adult”
Although families were acutely aware of the complexities involved in respecting their relative and enabling them to be their own person, their comments suggested that staff often failed to recognise this or think more deeply about the tensions that management of risk, best interests and maximising service user choice and control might involve. It seemed that many of these tensions juggled by staff at the frontline and at more senior levels of the organisation were invisible to family members. Many expressed the view that greater transparency was needed about what could be expected by service users, in particular how decision making about choices expressed by their relatives and risks were managed. They said for example,

The system needs its consumer side…some sort of documentation that says, ‘if you go and live in this facility’…Take the trivial example of the toothpaste, it says, “You can elect to have your teeth cleaned, once or twice a day, whatever you like, and with whatever toothpaste you like…and basically you can have a choice, and we recommend this but you can have the choice”. Then that should be reflected in the manual as well so the staff there know that they’re responsible to make sure that oral health is considered with this resident but they can’t force them (5F).

I want to suggest all services need to have a dignity of risk policy so that they have got something to hang their hat on if something goes wrong, we’ve been following this policy and okay things go wrong, but that’s better than being damned for never letting anybody take the chance…if anything this is what’s missing in support services is that no one can take a risk, not allowed to take a risk, and the whole works, just stops anyone. Dignity of risks and duty of care and then put the two together, and have a policy around those two concepts (4F).

**Staff-service-family collaboration – ‘there’s discussion with me about what I think’**

Quite spontaneously many families talked in some depth about the difficulties of their relationships with front line and more senior staff in supported accommodation services. They also talked about their frustrations with the major funding body, the Department of Human Services, and of making complaints to bodies such as the Office of the Disability Services Commissioner. Their comments suggested a final element of respectful practice which was largely missing from the services they had had experience with. As the comments from family members in the sections below illustrate, the main themes of this element of
respect were described in the negative. Family members indicated that respectful practice by staff and organisations should include: recognising the role that families play in the lives of service users, giving due consideration to their views, responding in a timely way to issues they raise and displaying greater honesty and transparency in the way services are delivered and the extent to which policy visions are being realised in practice.

Disrespected and demonised – ‘why didn’t they tell us’

All except one family talked about the difficult relationship they had with frontline staff, who did not value their views and at times actively excluded them from involvement in their relatives life. A brother for example, felt that his role in his sister’s life was not sufficiently acknowledged, saying,

Me being a brother, means when I talk to some staff their mindset is that I’m not authoritative, even though another client’s mum can be in there going, ‘oh, she can’t have chocolate’, and they go, ‘well, your mum said’ (1F).

Many parents expressed a similar frustration to this brother, saying that neither they nor their views were respected by staff. They suggested that staff were unwelcoming, uncooperative and often did not pass on information about their relative. They said,

Why didn’t they tell us? This is not unusual; they don’t tend to tell us about injuries. Now had she not re-broken her ankle or whatever in April we wouldn’t have known …I never feel welcome, I really don’t feel welcome…I don’t ever for one minute think they’re deliberately hurting Cathy, that’s never been my intention, what I get upset about is they don’t tell us, and if there’s a problem with her I just want to say to them, ‘if you’re having trouble then, ring up and say what do you think we should do? I think they’re hoping we’re just going to get sick of them, we’re going to get sick of it, and just go (9F).

So it doesn’t matter what we say it will be the opposite. It wouldn’t matter if it was daytime, it would be night time, that’s the way it seems…that point of ridiculousness, and it really is just such a waste. There is no respect, we are guardians…That is exactly the problem when somebody lies to you (11F).

They didn’t tell me, and I believed it was going ahead…a bit of arrogance that, [staff think they] are in charge, and they’ll make the decisions, thank you very much, which probably bubbles up where you’re wanting to do something a bit different, and maybe, also they feel a bit challenged (4F).
Only one family were positive about the respect that staff had for their views and felt they were involved in a respectful way about decisions in their son’s lives. This family said,

Oh, I think he is offered opportunities and they test them to see whether it’s something that the guys want to do, or achieve, and there’s discussion with me, about what I think (8F).

**Disempowered families – “we just don’t get listened to”**

Families pointed to power imbalances; the enormous power held by DHS and other service organisations over service users lives compared to their own. As one said, “you know we have got no power, us parents” (2F). They felt that service providers resisted making change in services and were reluctant to investigate the issues families raised. Family members said for example,

It’s power of control, and they, I mean, DHS have ultimate power, over residents and families, you know they can force the residents to do anything they like, and they have no ability to do anything about it and even families…And if you actually stand up, if you’re not intimidated, then…DHS try and stop you from finding out what’s going on, they impose all sorts of restrictions, you can’t go into a house unless you ring first (5F).

Well they’re caring for the most vulnerable members of our society…well caring is not exactly the word I’d use, but they’ve got those in their power, yes, that’s the frightening bit (11F).

The Department is in defense, in denial. I mean they totally defend against doing anything…they’ve got a million reasons why they shouldn’t do it…you don’t report it to the house supervisor because he will spend his time defending the staff…they really believe they are above everyone…issue avoidance, dodge, weave, maneuver, every which-way, to get out of everything, there is nowhere you can take anything, … they took no notice of us whatsoever (3F).

I used to have six weekly meetings with the manager, for what, five years, nothing changes, meetings with the CEO a few times, and he was just such an arrogant bastard it was a waste of time, the regional manager, nothing ever improved, they will back the staff (2F).

Families were aware of complaints procedures and the independent bodies established to
monitor quality and safeguard the rights of service users. However, they saw little point in complaining, describing the toll it took on their energy for the meagre changes that resulted. As one parent said, “well what’s the point, nothing ever happens”. Others said,

It’s a continuing battle, fights, at one extreme raising issues at another, little change or response…it just goes around, and around, and around, and around, and around” (5F).

Oh it’s terrible, and there’s been staff that’s stood down, and this woman, who was currently at the house, the team leader’s, absolute poison…staff have put in complaints about it, families have been putting complaints about her, but nothing has happened, she is still operating from the house (12F).

Other families pointed to the slow responses and failure to follow through by those they complained to, saying things like,

She was going to get back to me, and she hasn’t (11F).

I really should have jumped up and down then, but I didn’t and I was stupid… but I was over it...Because over the years I’ve just been so frustrated… because we just don’t get listened to, they just don’t want to know… And we complained about that earlier and the regional manager said, oh yes, we’ll look into that’….and she hasn’t done a damn thing about it (9F).

Several families suggested that the processes were not always correctly followed, alleging that evidence had been falsified or a covered up had occurred. They said,

They don’t follow their own policies and procedures on complaints…and it’s not one case, if you take something like this…an incident form, an incident in which something happened to our son, it is nothing but a falsified document, and this here is an incident that occurred in July, 2011, right, so when was it written? (11F).

We’ve been trying, for over 12 months now to get somewhere, get some answers, and basically they’re shrugging their shoulders, and saying, ‘no, we don’t know’, no apologies, no nothing, just, ‘we don’t know’, and now they’re trying to tell us that when Cathy was being dressed in November and fell of her bed she was sitting on her bed with her feet planted flat on the floor….That’s a dead-out lie, she can’t reach the floor….She physically cannot sit on her bed,...what I’m upset about is the secrecy, and the changing of their stories, because in these reports here, there’s a different story (9F).
Families were also disillusioned with the capacity of independent bodies to monitor service quality and adequately fulfil what families perceived as their legislative roles. As one family member said,

You try and go to the charter of rights, and responsibilities, it’s the Ombudsman …they are in power, to take complaints…you try and complain…it always comes back to what’s reasonable, and they say, ‘well DHS says, it was reasonable that he did this terrible thing to this person so the Ombudsman says, ‘oh well, that’s a good reason-well, end of story’ (5F).

Almost all family members mentioned the slow response, or limited power and influence of the Disability Services Commissioner, saying for example,

Disability Commissioner was interested but we haven’t heard from him in eight months? He was going to look into it too…didn’t hear from him, he’s useless, waste of time (9F).

The Office of Disability Service Commissioner is a useless organisation…never had one complaint solved with them, they’re totally useless, because they can only do conciliation. What a waste of time that is…except where it’s a simple thing…where they’ve got some simple little case, but none of our stuff is simple (3F).

I considered going to the Office of the Disability Services Commissioner, or the Ombudsman, or whatever it’s called, but, a couple of people said, they actually don’t have any teeth, and they take a long time to respond to anything, and I thought, I can’t be bothered (6F).

It’s better than nothing, I would have had nowhere to have my issues addressed, but the Commissioner has no power. Your big problem is with the staff…they can’t make like DHS or Tiboon force staff to leave (2F).

As well as this sense of frustration and futility, families pointed to various other reasons that deterred them from making complaints, most commonly the response of staff or managers, fear of being belittled or the potential of negative repercussions for their relative. They said for example,

I’m a person that steers clear, because I know the repercussions that are going to happen, and they certainly happen now (12F).

I think they thought I wasn’t going to push, and finally when I did push, even the
initial response I got back from the senior manager was that I was the big bad brother, and there was nothing wrong with her (1F).

We’ve allowed them to fob us off at the house level. Simply because I’ve always felt a barrier up there anyway, they don’t particularly like me…no one’s going to listen to us anyway, and, there’s this real barrier between us and the house, and I certainly see it, that the house just don’t want to talk to Mum (9F).

You know some agencies treat parents like the disabled family, so because you’ve got a disabled child you must be pretty loopy yourself…the Department are totally and utterly disrespectful, they don’t give you their phone number, you have to go through the number system to get anyone to talk to you…I talked to the head honcho at one stage, and she just got terribly upset with me. That’s when I was talking about the subtly of intellectual disability and the culture of the organisation (6F).

Disillusioned by empty words – ‘it's pages of waffle that nobody reads’

All family members felt they were well informed of the legal and policy frameworks that govern the provision of disability services and the organisational documents that flowed from these. They were disillusioned however, with the capacity of services to deliver on policy intentions. In describing the many failures at individual service user and system levels, they consistently drew attention to the empty or meaningless words of policy which they saw as having little impact on practice in services; good intentions on paper but poor execution in practice. Referring to the state-wide policies family members said for instance,

Currently what I saw was out of step with the State Disability Plan, no friends or companions, discouraged from accompanying a person in regular community life activities (4F).

The Disability Act, 2006, is a waste of time, right, it’s a total waste of time, there’s nothing there (11F).

Talking about the organisation that delivered services to his son, another family member said rather bluntly, “but it’s just waffle, it’s all these mission statements, they’re bloody crap” (2F). Referring to the DHS practice manuals one family member said;

We’re all aware of them….they’re very good…but they’re not implemented…I mean this latest one they’ve really gone to a lot of trouble to get this right, and there’s a lot of really good stuff in there. We’ve got a lot of our inside contacts, particularly house
supervisors, and we’ve said, ‘have you got a copy of this?’ …’oh, well, somewhere, I’m not sure where’, ‘and have you read it?’ , ‘oh, well, not really’ … so they’re really not interested (3F).

Closer to the frontline of service delivery some family members talked about the meaninglessness of tools introduced to support good practice, such as individualised planning procedures. In one families view these had led to plans that were never implemented.

I mean we do the PCP [Person centred planning] which is the most absurd thing that ever walked this earth, like it contains no real information, its pages that nobody reads. I’ve asked staff, ‘have you looked up there’, ‘oh no, we haven’t got time for that?’ …it’s not readable, it doesn’t make sense…every year they promise that they’re going to organise a holiday for her…why talk about it, it never eventuates, it’s not going to happen…writing all this down for nothing to happen (12F).

The extent of disillusionment families felt about services fell along a spectrum. Most fell somewhere between the two families for whom advocacy occupied much of their time and the one family who were very satisfied and optimistic about the complaints mechanism in their son’s house. The emotional energy advocacy consumed for the two families at one end of this spectrum, and the effect of continual rebuff was evident from their very detailed accounts and the voluminous paperwork they had amassed. The failure by the service system to deal in a timely or appropriate manner with their concerns or mediate conflicting views had meant that seemingly minor issues took on mammoth proportions. In contrast, at the other end of the spectrum, an optimistic family member was able to give an example where an organisation had acted swiftly when something had gone wrong. She said,

There’s a complaints mechanism written in plain English on Daryl’s board, in his room and all of the guys have it, so that you know if there are any issues they can be escalated through house supervisor or up to the CEO…And I’ve got no doubt that if Daryl had some concerns that staff picked up on, if we picked up on that it would be handled…certainly within this organisation they’ve had a [staff] issue but it was dealt with (8F).

**Greater transparency and collaboration with families**

As has been very clearly illustrated many families felt alienated and disempowered by staff at various levels in the organisations that provided a service to their relative. They felt unwelcome and often excluded from consultation and decision making. Families saw
however, the potential value of genuine collaborative relationships between staff, family and others involved in their relatives’ life. In their view all held a similar position of wanting the best quality of life for the person with intellectual disability and a more open, less defensive stance by services could enable better learning from incidents where things had gone wrong, so poor practice wasn’t repeated. They said for example,

We’ve got to change Human Services policy to make the staff more accountable and more transparent…and see that none of us parents are looking for things to pick on that’s not what it’s about. But of course, when something goes wrong we’re not going to say: “Oh that’s all right, dear, never mind” to the staff, we’re going to say, “What happened? Yes, so it doesn’t happen again” (9F).

The reflections of two families about their current very positive relationship with staff gave some indications of what good collaborative practice might look like. They said,

My overarching awareness is that the organisation has the people, their wishes at heart, even though they’re nonverbal clients, they’re always putting things by them, or the families. Families are fully involved, where their families are engaged you know…They’re asking for feedback, asking parents, what would they like, what do you think would work for him, that would make it more homely, and things like that (8F).

Now these people…we call it the “A team” are doing it really well. They were telling us consistently what they were doing and so much so that we’d come away and say, “we really do have to go”, and they kept talking to us, and we’ve actually had his key worker used to ring us up and say, I’m on my way, and we’ll drop in, and tell you about something. ..Put the kettle on, I’m coming round”. Nobody ever did that before… (3F).

**Family Perspectives on Respecting Dignity**

Although frequently families used the phrase ‘respecting dignity’, respect and dignity were not always used interchangeably. Dignity was a more personal concept, associated with social acceptability of personal appearance and privacy.

*Social acceptability - ‘you don’t want her going outside looking ridiculous’*  
Personal appearance was seen to be important both to a person’s own sense of themselves and the way they were perceived by others. As one family member said, appearance is
Because it’s so much easier to talk to someone who’s presentable and, I don’t mean that he’s got to be spit and polish, but you know, just tidy … so if they don’t look nice when they go out, that tells the community they’re really not worth worrying about (10F).

Similar to choice and control, family members saw that people with intellectual disability required support with personal appearance. Most commonly they talked about wearing appropriate clothes and having well cut hair. As one mother said about her daughter, “she does a lot of that herself, but she needs fine-tuning, you know, you don’t want her going outside looking ridiculous, sort of a purple top on and pink shorts or something” (2F).

As well as not giving appropriate messages to the general public, parents talked about the embarrassment either themselves or the person with intellectual disability experienced if they were dressed in appropriately or in an unkempt manner. They said for example,

I’ve been embarrassed, and it’s twice I’ve got in complaints about it… they’d met me in Frampton with Shelia, dirty stained clothes on, long hair, big hair knots, I could see it straight away… I knew her hair hadn’t been brushed (2F).

Well hair cutting I think’s important. Because he went off to the tri state games, and here he is in all of these wonderful photos… he’s a handsome young man, and he likes looking nice, and he likes going out (10F).

We’ve had to restrict what clothes she has … she was going out looking disgusting, she has a pretty curvy shape that’s sort of a bit plump, and she was wearing tight leggings, with a tight top… and just even the day program staff said it was a bit inappropriate, or not suited to the weather, or mismatching, and things like that… They don’t necessarily look at whether she needs more support (1F).

**Privacy - ‘just knock before you go in’**

Privacy was understood to be an important part of dignity - the right to a personal space, such as a bedroom and to receive sensitive personal care. One family in particular talked about the way their son’s privacy was respected by having a separate book about his personal care that was not as available to anyone, in the way that his communication book was. Other things they mentioned were about the privacy of his bedroom and provision of personal care,
But just the knocking on the bedroom door, before going in, and asking him, or always telling him what they’re doing…they have it in simple language about respecting other people’s privacy, so each individual person will be told, and be shown, and if they do go to enter someone’s [room], they would be shown, that is a respectful thing not to go in, that this is so and so’s room, not your room (8F).

Another parent recalled the way a staff member had balanced privacy with providing support for showering. She said,

A lot of the dignity comes with respect as far as the showering and things like that, yes, she’s entitled to dignity, and privacy but at the same time she needs to be supervised for medical reasons, showering, not just her skin condition, she’d turn the hot on, before the cold…[she the staff member told me ] Well, you know, I don’t stand there the whole time. Well this morning I actually folded up all the spare towels and everything, and every few minutes I was just yelling out, ‘Oh, have you done this, have you done that?’ and went through the list (1F).

Many families described situations where they felt a person’s dignity had not been respected. For example,

Yes well dignity goes in with respect, I mean what often happens is, and depending on the level of personal support that people need, they can be left naked, they can be belittled with their toiletry needs…when staff are doing something for them they talk across them…sometimes you see two staff, talking about their boyfriends (5F).

The other lady comes out of the bathroom, or out of the toilet, seeking help, with no privacy from the waist down, that is not dignified for her (11F).

**Family Perspectives on Potential Abuse of Rights Vignettes**

The 6 vignettes about which families were asked to comment are in Table 1 over page together with a brief summary of the main points they were designed to illustrate. They stimulated discussion about respect and abuse of rights, much of which has been captured in the earlier sections. The vignettes helped families to reflect on both these and similar incidents they have witnessed in supported accommodation services. Families explained why these incidents might have occurred and the alternative actions that staff might have taken. Primarily they thought staff members should be better briefed about service user preferences and supported to understand the underlying reasons why people might behave in particular ways. In particular they alluded to the likelihood that casual staff might make assumptions
about norms that operated in a house that could undermine the exercise of choice and control by service users. All families thought that vignettes 5 and 6 portrayed clear examples of sexual and physical abuse. Most families had similar views about the other 4 vignettes and thought they illustrated inappropriate use of power and control by staff that resulted in an abuse of service user rights. However, several families were less certain that an abuse of rights had occurred in each of the first 4 vignettes.

In the first vignette, a staff member sought to override the choice of a service user about where she ate her meal. All except one of the families saw this as disrespectful and the undue use of power and control by a staff member. They said things such as, “power play… big problem” (2F), “not respectful” (3F) and “disregard of choice” (4F). Only one family member was slightly more equivocal and thought the situation “wasn’t black and white” (10F), suggesting it was usually nice for people to sit together to have tea.

There was similar majority consensus about the second vignette, involving a supervisor threatening a resident who displayed challenging behavior. Families commented that it portrayed “abuse’ (5F), “totally unacceptable behaviour” (7F) and “a threat of violence” (11F). Two family members (2F, 12F) leaned towards the view that as long as the staff member did not follow through on the threat to hit the service user back then “it’s a fair thing”.

All but one family member (12F) thought that the actions of staff in the third vignette, involving preventing a resident from leaving his room by jamming the door shut with a chair, constituted an abuse of rights that amounted to illegal seclusion and posed a danger to the service user. They said for example, “that’s illegal” (8F), “reportable” (4F) and “imprisonment, dangerous” (11F). One family member, however thought that using a chair against the door handle to stop a service user from coming out of their room was acceptable if there was no other alternative.

The fourth vignette, involving a staff member withholding lollies from a service user until he said ‘thank you’ was interpreted by families as an attempt to teach manners. Most agreed this was an important aim but the method used was not appropriate and constituted excessive use of control and demeaning behaviour. They said for example, “teaching manners is ok but not like that” (11F) and “totally inappropriate” (5F). One family member (12F) suggested that a similar approach had worked with young children and was less concerned about staff behaving in this way than the other family respondents.
### Table 1 Vignettes

<table>
<thead>
<tr>
<th>Description</th>
<th>Issues Raised and Possible Justifications</th>
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<tr>
<td>1. Dianne is in her 50’s and lives in a group home with four other people. She likes to eat her dinner on the coffee table in the lounge room whilst she is watching the TV. All of the other ladies eat their dinner at the dining table together. A casual staff member was on duty when Dianne picked up her meal and went to the lounge room, as usual. The staff member said “I don’t know what you think you are doing, but you can sit in here with everyone else thanks”. Dianne said nothing and sat at the dining table with everyone else, whilst constantly looking over her shoulder straining to see the TV.</td>
<td>Countering right to exercise choice and control</td>
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<td>Possible justification:</td>
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<td>2. Ahmed is a young man with autism and he lives in a group home. Sometimes, Ahmed can become upset and may hit other people. The supervisor of Ahmed’s home says that he has come up with a good idea to stop Ahmed from hitting others. He says, “I tell him, if you hit me, I will hit you back”. The supervisor feels that this is a ‘normal human reaction’ to being hit and that it works wonderfully well, with Ahmed not hitting anyone for a long time.</td>
<td>Intimidation and control by staff</td>
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<td>Possible justification:</td>
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<td>3. Anne is a staff member at a group home where all residents have very high support needs. Michael, who lives in the house sometimes goes into other people bedrooms and will sit on their beds. Unfortunately, Michael sometimes has a bladder or bowel accidents. All staff, especially Anne thinks that this is terrible and that Michael should be stopped from going into other people’s rooms, especially if he soils their beds. Anne thinks that Michael should be locked in his room at night, and she has figured out that if you jam a chair under the door handle Michael can’t get out. Anne thinks that this is fine and perfectly OK as Michael will try the door handle once, then give up and go to sleep.</td>
<td>Countering right to freedom to move about their own home – seclusion.</td>
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<td></td>
<td>Possible justification:</td>
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<tr>
<td>4. Marco has a severe intellectual disability and doesn’t use words to communicate. Marco likes lollies. Marco was sitting in his bean bag and he signed to the supervisor that he would like a lolly. The supervisor got up to get</td>
<td>Exercise power and control over service user in a manner that is dehumanising, disrespectful,</td>
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Marco a lolly. She held her finger up and said to him ‘staaaaayy’ in a firm tone. Marco tried to get up, but she again held her finger up and said ‘staaayy’. She came back with a lolly. She held it just out of Marco’s reach and said to him ‘what do you say?’ Marco didn’t respond, so the supervisor still held the lolly out of Marco’s reach and repeated ‘what do you say?’ Marco tapped his chin; ‘thank you’. He was given the lolly, and the process was repeated before Marco could have a second lolly.

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<td><strong>rude and belittling.</strong></td>
<td>Reinforced stereotype that people with intellectual disability are animal like.</td>
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<tr>
<td></td>
<td>Possible justification: Teaching manners and social etiquette</td>
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5. Freya likes to watch TV in her nightie after having an evening shower. When it is hot, Freya wears a light summer nightie, that is quite short. Freya has diabetes and to help with the circulation in her feet, staff sometimes give her a foot rub. One night, Paul the staff member was rubbing Freya’s feet. He noticed that she was completely absorbed in watching the TV programme, and he began to rub higher and higher up Freya’s leg. He slipped his hand up Freya’s nightie and she continued to watch TV, seemingly not noticing where Paul’s hand was.

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<tr>
<td><strong>Sexual assault.</strong></td>
<td>Exercise of power and control over service user</td>
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<tr>
<td><strong>Possible justification</strong></td>
<td>No harm done as she didn’t seem to notice.</td>
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6. Jodie doesn’t like any of the other residents who she lives with. She can be difficult to support and at times she can be seen as very unreasonable. She has Aspergers and an intellectual disability. If the other residents have been in the kitchen when the staff are cooking Jodie’s meal (she doesn’t want to cook), then Jodie will become very very angry. She will insist that staff make her something else. One night, a staff member refused to make another meal. The staff member felt that Jodie was being ridiculous and that there was nothing wrong with the first meal that was prepared. Jodie got upset and started to hit the staff member. By now, the staff member was getting angrier, she picked up a nearby broom and shoved Jodie with the broom handle. Jodie was still lashing out, trying to hit the staff member. The staff member then shoved Jodie into her room using the broom handle.

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<tr>
<td><strong>Physical assault</strong></td>
<td>No understanding of reasons behind service user behaviour</td>
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<tr>
<td><strong>Possible justification</strong></td>
<td>Self defence</td>
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<td>Reasonable response to an unreasonable demand.</td>
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Family Perspectives on What Makes a Difference

Families’ consistently pointed to similar factors that they felt contributed to good staff practice and safeguarding the rights, dignity and respect of their relative in supported accommodation. These were: 1) strong front line and organisational leadership; and 2) willingness of families, staff and others to report problems and the tenacity to follow through.

Frontline and organisational leadership

Families talked about the significant role played by house supervisors in shaping the culture of supported accommodation services and delivering on high level aims. House supervisors were important in guiding and supporting staff performance and motivating staff by valuing their contributions. Families said for example,

The dignity and respect comes from the house supervisor. If you get a good house supervisor no problem…you can have a good house supervisor, and they will collect staff around them that reflect their values, and their relationship with the head office is usually sorted out (5F).

The house supervisor is such a pivotal role in that structure of respect and the culture within the house, because the organisation has to have the right culture, but the people on the ground have the attitude, and if the people that are working with a guy have an attitude of respect and support and genuinely wanting to give them the best. The house supervisor is sort of like the conduit, between the organisation and the staff on the ground. (8F).

Several family members linked the quality frontline leaders to that of the senior leadership in organisations, saying for example,

I don’t think that you can have the staff and the supervisors doing a good job, unless you’ve got from the top the right attitude (5F).

It needs to be inbuilt into every organisation, and if you’re a staff member working with these vulnerable clients …so you need to be seen, that you’re getting respect from management, too, and indirectly management are respecting the people who are living in these houses, as well. (7F).

Organisational leadership was also seen to be important in providing practice continuity and consistency, to counter the impact of staff changes. One family member captured the commonly mentioned negative effects that staff turnover could have if not managed well by
an organisation,

You get all this change, either the house supervisor changes, and everything falls apart, or you get a head office person change. They come in and a new broom sweeps clean and they disrupt everything, and well that’s a problem (5F).

**Willingness to report problems and the tenacity to follow through**

Earlier sections have illustrated that despite their knowledge of policy and mechanisms for raising issues about service quality, many families felt it was futile to do so and it cost them considerable emotional energy. Despite their disillusionment family members continued to monitor their relatives’ service quality and lodge complaints. Many spoke however, about the vulnerability of other residents in their relatives’ home who did not have involved family members and had no one to raise issues on their behalf. They felt that neither they nor staff were particularly well placed to represent the interests of these residents. Partly this was because it had been made clear to families that what happened to other residents was ‘none of their business’. Privacy and confidentiality policies had been invoked by staff to actively dissuade them from taking a broader view that encompassed the wellbeing of other residents. They said for example,

I know that it’s none of our business what the other residents are up to…just from observation a few of the other residents have no parents or family involvement whatsoever, other than maybe once or twice a year (9F).

I started taking photos, of lots of things because they couldn’t deny it, but that pissed them off, then they told me, I wasn’t allowed to take photos, in the house…it’s a breach of the other residents’ privacy (2F).

Responding to whether she would take action if she witnessed one of the vignettes described in the vignettes presented in the interviews one family member said,

I know that probably I wouldn’t be told why that person’s doing what they’re doing, that’d be confidential, or something, I’d probably still query it…I’d probably say something, yes, getting into trouble for it, but that’s fair enough (7F).

Reinforcing this sense of individuality imposed by staff over a more collective sense of responsibility for the wellbeing of all residents families referred to their isolation and lack of peer support for raising issues with service providers. One family member said that the organisation “have been resistive to families catching up, in the past though. Very resistant…because I think they’re worried about ganging up” (1F).
Relative isolation of families of service users, policies of privacy and confidentiality, as well as apparent resistance by services to listen to families concerns about other service users suggest an individualistic culture is encouraged. This meant it was difficult and rare for anyone other than family members to speak out which left people without involved family vulnerable to having no one independent from the service to raise issues on their behalf. The value of having people other than staff involved in a person’s life was highlighted by this example, where a family member recalled an external community friend had reported a resident had been abused. She said,

He is doing, - a run with a guy who was doing garbage collection of stuff from schools. Roger was his jockey whatever they call them and so he made friends with this young guy and that was wonderful for Roger. He had this friend, and he cared about him, and he was the man that broke the story about Roger being abused. Because apparently Roger said something, while he was in the car with him one day and which rather shocked him and he asked him where he heard that and he said oh, yes and he told him. And so he told his boss, and the boss said he’d go and see the principal, but he said nothing happened so he went to the police, and of course then…(10F).

Compounding the problem of some service users having no one to speak up on their behalf, a number of family members suggested that it was often difficult for staff to speak out about poor or abusive practice. They said,

There’s a lot of problems with the staff being able to put their hand up and say, “That’s not right”… and it can be all the terrible stuff like assault, all the way down to just not being treated properly and there’s really no mechanism for the staff to say: “Look, I don’t think that’s right” and anybody who really puts their hand up… they get their head chopped off (5F).

I really get the feeling that some of the staff don’t feel confident and safe to speak up, when they see things they’re not happy with? Of course they’re not, they’re frightened that they’re going to lose their jobs (9F).

**Staff Perspectives on Respect – ‘it’s the little things that really matter’**

The perspectives of staff about respect mirrored in many ways, those of families. They talked about examples of dignity and respect from their own practice and alluded to the importance of “how it applies to people” and “being able to transfer what they know from the
Act, into what it looks like in practice in the service” (CD). Staff tended to have a greater focus on positive examples than families, but also gave examples of poor practice they had witnessed and broader aspects of the service system that obstructed good practice. Staff drew attention to the expectation about respect applicable to their role in services, compared to normal expectations that respect had to be earned. One said,

Generally we think about respect in the wider community as something that you’ve earned, that respect in a respectful relationship between two people you kind of you’ve earned so much respect…but I think in terms of service-provision it’s a given, regardless of who we’re supporting and what level of respect they give back to us. (CD).

In a very similar manner to families, staff drew attention to ‘the little things’ and the cumulative way in which every day actions, interactions and “changing our attitudes every day” (GH) could build a culture of respect. They said for example,

You know it’s just the little things, that’s making sure that you’re not making a sandwich for yourself without offering someone else, especially if it’s lunchtime. You’re not watching TV up past bedtime, and keeping people up…and not changing the channel while someone’s sitting there watching a TV show, you know, it’s I suppose little things? (GH).

One of them goes swimming with a personal trainer once a week, another one goes to the synagogue, and has been for quite a long time, and so they’re all these little things that you can actually see, and they must count in that person being much happier for what has happened and comes from that, ‘I’m valued, and I’m respected’ (AB).

As families had done too, staff suggested attention to minor transgressions of respectful behaviour by staff were important as these could escalate or be indicative of a pattern of behaviour. Talking about the role of front line leaders one staff member said for example,

And being able to pick people up when there’s a small kind of stepping-outside of the boundaries rather than waiting until it gets to something big, like shoving a chair under somebody’s door…how often do we see this sort of stuff it’s not out of the blue, this is, you know, if we think about the way a person’s been working, if it was kind of a habit (CD).
Elements of Respect - Staff

*Regarding each individual as their own person – ‘she has a right, it’s her house not yours’*

In a similar way to families, staff talked about the importance of seeing each person with intellectual disability as an individual human being with the same right to be treated with respect as other members of the community. As one staff member said about the people she worked with,

> Seeing these people as individuals for one, not just as a group home…everyone’s the same, they’re people first, a person with a disability, you need to treat them as people, and people that have got goals and, you know, they need to be respected (GH).

Another said, “it’s respecting the person’s rights, but also respecting them as a human being, and not seeing as a disability…Yes, back, back off…she has a right, it’s her house, not yours” (RB). While pointing to the rights of people to have their own values acknowledged, staff alluded to how difficult it was to do this, saying for example,

> If you [are a staff member and have] three 20-year old daughters at home. You come to work, and there’s 20 year old girls, it really hard not to say to them [what you might say to your daughters]. But at the end of the day, they’ve got their own mums, but that’s not our role, our role is to support them with their everyday needs, and to guide them in the right direction, not tell them… so you’re remembering they’re not your child (GH).

Respect that the person with an intellectual disability has opinions and preferences, and individual personality, just you know like someone without an intellectual disability, so there’s just respect for those opinions, and just what forms their whole personality. Because it comes back to individual worth the bottom line is every individual is worthy of our respect…it’s to listen and hear what the person’s saying, it might sort of be different to what you thought (CD).

The freedom to have, to make, and, choose, your own decisions, along the way…Without constraint. So to have the knowledge, to have the freedom, to have the support, to make, the decision that you choose to make…So it’s your duty of risk, to respect that person and …respecting that person’s choice (EF).

Staff suggested that their role included encouraging service users to explore possibilities, take greater control, take risks, and make demands on staff. As staff members said,
In my previous role I did a lot of work with the service users to just encourage them to say no, and to know that it’s okay to actually say no sometimes, not always say yes to staff all the time (CD).

He’d seen some recipes, and wanted to make a banana smoothie and he wanted a banana cake, but didn’t realise that he could tell staff that that’s what he wanted, and he could do it, and he was shocked, when Helen said, well if that’s what you’d like to do, you’ll do it (AB).

But letting her learn, letting them cook the dinner and putting in what they want, and if it doesn’t taste too good, well, you learned, but yes it’s just, not holding people back (RB).

One staff member talked about a recruitment interview she had been involved with, together with one of the people with intellectual disability she supported, which had tested out the attitude of potential staff members about choice and control. She said,

The right reasoning is they’re there for the clients and this came out. One of the questions asked by one of the girls was, ‘where would you take me, when I want to go out?’ and everybody was, ‘oh, I’ll take you to the movies, I’ll take you to the cinema, I’ll take you to different things’. The guy who didn’t have experience, said, ‘I’ll take you where you want to go’ (AB).

Enabling support – ‘what can we do to support you’

Like families, staff saw a strong connection between respecting a person’s right to control their own life and the enabling support to do so. The staff from one of the organisations talked about its emphasis on the use of person-centred active support as an approach to practice that was about, “breaking that ‘we will do this for you’, turning it back and saying, ‘what can we do to support you, so that you do that for yourself” ” (EF). Staff from another organisation echoed this sentiment, saying their role was “trying not to take any of their independence away, so encouraging them to do things for themselves” (RB).

Staff illustrated the thoughtful practice needed to support people to retain control over their own lives or be respected in the community. For example, one talked about how he attempted to avoid situations that might be challenging for one of the men he worked with or that might lead to behaviour in the community that could impact on his sense of dignity and the communities’ sense of respect for him,
Staff 1. If you’re working with someone with a behaviour of concern, have the foresight not to put them into a situation, especially in the community, where they’re going to display those behaviours. Staff 2. You mean like set them up to fail, kind of thing. Staff 1. Yes, but it’s just taking that extra time and extra bit of planning, not to put them in the situation that’s going to be too much for them, based on our knowledge of them…just to be aware of it (CD).

Another staff member pointed out that staff often fell into routines of doing things for people without checking on whether help was required or not. She described how she had noticed how the sleeves of a woman she worked with were too long and had taken care not to take over and fix the problem without checking with her first. She said,

The cuff of her jacket came over her fingers, and that’s the first thing I noticed when I walked in the room. I said, cripes, it’s so cold, so I suppose your fingers are just so cold, and she said, yes, and I said, so I can see that you’ve got your hands nice and warm. I was trying to check out is that what you want or, do you want me to do something with them…I said, do you want me to roll them up? and she couldn’t wait, for me to roll them up (AB).

Some staff felt that providing information or offering alternatives about which the person might not be aware, were important ways of enabling service users to make more informed choices. In an absence of adequate support some staff felt that ‘client choice’ was used as an excuse for poor practice, and a hollow concept. In a very similar way to families, staff were aware that service users could be easily manipulated or poorly supported by staff. They said for example,

One of the things that staff, including myself can get themselves in trouble with is that it’s, ‘oh, Johnny doesn’t want to have a shower, tonight’, and he hasn’t showered for two weeks, but it’s his choice? And it’s like, ‘well what information have you given him, to make that decision?’ So sometimes we help the client make that decision, they don’t want to go to school, they don’t want to work, they don’t want to go and see their mother. But how, what information have you given them, considering that they do have an intellectual disability? And that’s one of the biggest things. So, you know, it’s about providing that information, and then respecting their decision…because otherwise you can start…running a person’s life, under the guise of, oh it was their choice, and respect their choice’ where, you didn’t respect them enough to give them
that info (EF).

If they wanted to wear something that looked maybe not quite right but was their choice, it’s suggesting other ways, there’s ways, like going, oh what about this one, though and keep trying (RB).

Staff 1. Where they went out wearing a holey old t-shirt and a pair of pants falling down around their knees every five minutes…Staff 2. And no one wanted to say hello to them …Staff 1…but that’s what they wanted to wear that day, so we kind of used that choice thing to mask what we haven’t done to support someone, properly (CD).

*Sensitivity through interactions and language - ‘changing words we use and the way we speak’*

Like families, staff talked about language and social interaction as being important markers of respect for people with intellectual disability. As one staff member said about respect,

I think it’s actually changing our attitudes every day. I think just changing words we use and the way we speak to them and not you know giving food as rewards, and bribing people and these little things, that give us that power (GH).

Using very similar examples to those of the families to illustrate respect, staff talked about actions such as; knocking before going into someone’s room, not talking over people or ordering them about, making sure to tell a person before you did something to them such as move their wheelchair or help them to eat.

Always be talking to the person, not talking around them to other staff, which is something you can see quite a lot (RB).

And it’s just letting them know, you know, that, ‘I’m going to leave you for 10 minutes…I’ve done all the things for you, but I’ve got to go and just help Jane get herself ready’…And just checking that’s right, so you might not be able to do one on one, but it’s being respectful, that you’re letting them know this’s what the situations like (AB).

Staff have to knock first, before they go into the client’s home, that’s usually overlooked…You’ve got things like staff need to ring the doorbell, before they go into the house, some staff have keys, they don’t do that, they just walk in, just those small things, if someone’s coming into my house, they obviously knock first on the
door, but stuff like that always gets overlooked, it’s like when staff are feeding the clients, instead of telling them first that, ‘I’m giving you something to eat’, sometimes they don’t remember to do that, so just those small things, I think, they’re the really important ones, because they’re on the really personal level, whether you’re feeding someone, whether you’re toileting someone (CD).

One staff member talked about the common situation where staff created a disrespectful interaction by stopping a person doing something and then doing it themselves in front of them,

Staff 1. There’s a classic of a staff member saying to a service user, we’ve seen it time and time again, ‘no, you’ve had enough coffee for today’, and it’s the prompting of the question from the service user is because the staff-member’s making coffee, so they see the staff-member come in and make a coffee for themselves and go, ‘oh, I’d like a coffee’, ‘No, you’ve had too many today’…Well look at it…you’re in my home, sometimes drinking my coffee, and telling me I can’t have something that’s mine. Staff 2. So it’s twofold, don’t be obviously making a cup of coffee in front of someone who wants one too, I mean it’s two sets of actions. Staff 3…it’s creating a situation where you’re forced to disrespect someone. Staff 2. Yes. It’s rude (CD).

One staff member talked about how easy it was to talk about using sensitive language but in practice to simply revert to habitual and less respectful language,

I see people do person-centered support training, and they can actually talk about it, like they know it, but when they go back to the way they actually act, they still will fall back on the values that you’re brought up with which may or not be appropriate (CD).

Another staff member talked about how staff could damage a service user’s reputation by the language they used. She said, “they can pass negative things on: ‘be careful of this person’, or ‘don’t give this person too much time, either they might want all your attention’” (CD).

**Taking time to find out - ‘so you’ve really got to read’**

Just as families had done, staff talked about taking the time to find out about a person and to read summary information about them or file notes, as an important element of respect. As well as knowing about specific health condition, staff thought knowing more about a person was important to tailor the type of support they provided. Talking about another staff member’s knowledge of a service user a staff member said,
So her knowledge about Kathy is just, you know, you can’t put a price on that… Well, each person’s different, so you’ve really got to read about each person to know, and like Kathy for example, I’ve got an approach with her, that I use a bit of humour (GH).

Staff also referred to the importance of writing file notes to ensure information was passed to others. They said,

I think making sure it’s recorded in all their programs, that they choose where they can go, and that it’s expected in the house they choose where they sit (CD).

The notes, that should have been left, support notes, for those people, should all be written up, so the staff know (RB).

Several staff were more hesitant about relying on previously acquired information about the people they worked with, and highlighted the dangers of out of date or inaccurate information, and the importance of always keeping an open mind. They said,

Keep learning about a person… it’s that culture of, you know, here’s your plastic cup, because three years ago you threw a glass or a fork, and now forever you have to drink out of that cup. And you archive things after a while, then that history kind of a little bit gets lost, and then people can go, oh I don’t know why they drink out of this cup, let’s try them, they haven’t thrown a cup for the last two years, let’s try it (GH).

This plugs into the informative part of our relationships as well, how we model respect, I think, what happens quite often is there’s quite a lot of historical knowledge about someone, which is passed down and which is often inaccurate. I think if people with disabilities are afforded the respect, every day can be a new day…how do we effectively capture a model of respect that is fluid and moving and acknowledges historical knowledge, but acknowledges that its history (CD).

Staff comments also mirrored what families had said about the need to adopt a questioning stance towards a person’s behaviour. For example, one staff member said,

We’ve really changed the focus on how you look at a behaviour, not looking at the hole in the wall, but why the hole, why they put the hole in the wall…If you found out what’s making them angry in the first place, and you fixed it, they might not want to hit you (GH).

Although staff talked a lot about their relationships with families, none referred to them as
being important sources of information to know about a person with whom they might be working.

Navigating complexity ‘unfortunately none of these things are clear-cut’

Contrary to the views expressed by family members, staff were very conscious of the complexities of their work, and the fine line they walked every day between competing principles of duty of care, choice and control, managing risk and best interests; deciding whether a person’s choice was good or bad, should be respected or questioned. Staff talked most commonly about risk and the negative implications that might flow from respecting a particular decision, and the care they took not to let their own values mask those of the person they supported. They said for example,

We’re forever assessing them and judging what the risk is and determining whether they’ve made a good decision or a bad decision and all of that sort of stuff. So if we talk about respect, we have to respect the decisions that people make that we don’t agree with them as well (AB).

Staff 1. We touched then on risk, if people are making decisions, and we are respecting people’s decisions and choices that they make, if there is an element of risk, or harm, as a result of the decisions that they make, how does that affect the way that we respect people’s viewpoints? Staff 2. Oh I think there’s a responsibility on the service providers’ behalf to ensure that all known supports are in place to achieve something successfully, where there is no element of risk? (CD).

Finding out the best solution and the less restrictive, you’ve got to look at those two things when you make any decision (GH).

Providing appropriate support to manage risk, however, as one staff member said, was ‘not clear cut’. It involved, judgment, honesty, acknowledging parameters to choice, as well as negotiating skills with both the people they worked with, and at times their family members,

Working alongside people, with disability as people in the world and respect goes both ways, and it doesn’t mean you get absolutely everything you want, at every minute of every day, it means that life is a negotiation, a series of choices, but giving up as well…if a person with a disability gets to do that every day as well, makes choices, gives up stuff, compromises, but then gets a lot of what they want too, its respect. It’s not about everything that you want (AB).
By being respectful is being equally as able to say to somebody, ‘well that’s actually not something that you do’…we become so oversensitive about saying to somebody, ‘sorry, but, we actually can’t do that, or we don’t have the resources, or we don’t have the expertise, or whatever in terms of support that you can give people’. But the respectful part for me is actually having that conversation with somebody, and that saying to them, ‘you know, this is the way this is, we could look at something else, or we could maybe ask somebody else, but we actually just can’t do it’ (CD).

A staff member described how she managed risk and respected choice. She had arranged for a young woman with intellectual disability to talk with a psychologist who could help her understand staff’s anxiety about the risks of her choking if she ate chips. The psychologist also helped staff to understand the impact on the service user of their blanket position that ‘no she couldn’t each chips’. She said,

What we think is valid, has to go in with how the client feels, and how she wants to manage the situation, knowing all the risks about it. And she came to understand how the staff felt, when she was coughing, what their anxieties were and how much they felt that when she was at risk, and what they were trying to do was what they thought was best. They then heard how she felt, about what she wanted, and the risks that she would be willing to take. So that discussion had never happened before, around each person listening, to how it felt for each other, and the conclusion we came to was that she will have her chips, she had to be treated in a certain way…a lot of work was put in, but the outcome was just fabulous…Yes, and to me that’s what respect is all about (AB).

Staff talked about the difficulties of making judgments about perceived socially unacceptable appearance or behaviour that might damage a person’s reputation and impede their social inclusion. For example,

We have a young man in one of our services who loves to hug people, and we sort of went through all the things involved, you know, they shouldn’t be going up hugging people, and 90% of people in the public actually say, ‘he’s made my day (laughter), and our judgment is actually, you know, he judges people better than we do (CD).

Staff drew attention also to the boundaries that were placed around their own judgments by the policies and procedures of their organisations which often limited respect for the choices of the people they worked with. Two staff members talked about this, saying,
Staff 1. That’s our biggest thing at the moment, working in such a risk-aversive, whether you say organisation or region or industry, or whatever the word is…it does impact on how much you will entertain a client having the choice and you know trying to show as much respect as you can, while also trying to cover your butt…it’s conditional what we do, encourage or support is conditional, because if it’s going to breach policy, you can’t do it, sorry. Which is awful, I mean, imagine that in our lives? Staff 2. Well, we’ve all got stories we can talk about, but I think, oh you know, we are bound by policies and procedures, legislation (EF).

Through their own self-awareness and experiences of working with people from other cultures, staff recognised respect was interpreted differently, depending on a person’s own values, rather than having a universal value. They saw the inevitable difficulties of differing points of view, in terms of consistency that this might create for the people they worked with. Recognising these difficulties led staff to one of the guiding strategies, discussed in the next section, that their own values should be left at home,

Sometimes it comes down to values, personal values, as well, you see it in everywhere and every kind of relationship, different values demonstrate different types of respect. My family you were brought up to respect your elders...another person’s family has a completely different interpretation, so yes I guess if you have 10 different support workers in a team in a house they’re all going to have very, very different behaviours around respect as well (CD).

**Staff- service - family collaboration**

It was notable that staff did not include this element of respectful practice that had been identified by families. They spoke little about the role of families in the lives of the people they worked with, according them much less importance than did families themselves. When they did speak about families it was usually to draw attention to conflicting views about risk, and the impact of family views on the dignity and respect of people they worked with. They said for example,

We actually see how they are disempowered by their families...because the family said no, then they’re not allowed to, and it makes it really frustrating… I guess they have a different expectation of that person …we actually think she can be a lot more independent, than what she is. And actually, it takes a lot of her dignity away, and it’s actually deskills her a lot, you know, which is really frustrating for us, and for her.
You know, for example she used to wait out the front for her taxi, and they said, so she can get kidnapped’, so now she has to wait inside, but she’d been doing that for two years (GH).

Staff gave a much more nuanced view of how they regarded family views than had been portrayed by family members, and often talked about the need to negotiate with families around conflicting views and values. One staff member said,

We have a Vietnamese person, chic, girl, her dad dresses her like a boy, hair cut like a boy, and we all thought she wanted to look like a boy…nobody questioned it until one day she said, ‘I’m not going to the butcher to get my hair cut any more’. It took a lot to get the dad to understand that she doesn’t want to go to the barber who used to butcher her hair. So once again it’s the dignity, the advocacy, and you’re just building those bridges, and not offending the culture side of it as well (RB).

Another staff member drew attention to the reluctance by some staff to tackle the values or attitudes of families when they differed from those embedded in current policies, and could be seen as undermining rights. She talked about the situation where an elderly parent was intruding into her son’s privacy, and action she had taken to negotiate this.

It’s necessary to tell staff or the parents sometime if he’s not being respected. I had one scenario where the client’s mother have been working in his room and while he’s having his private time under the doona, she said, ‘aye, what ya doing?’ And I had a staff come to me and say, that’s what’s she’s doing, but no one takes on the job to tell her, he is an adult now, can you stop this please, can you wait outside, can you have a coffee with me, can we just wait outside until he comes out, or something else, nice. We took things from there, we had a meeting with her, and they saw, so I think the key is sometimes, to take the initiative, because when it comes to parents that’s the hard part to talk to the parents (CD).

Staff from one of the organisations acknowledged the care implicit in complaints made by families, but they also felt that at times families could be disrespectful towards staff. As one staff member said about families,

And talking about respect, like they’re very, disrespectful to the way they talk to the staff, which makes it very difficult to work on shift. Yes they’re very consistent with their disrespect towards the staff, including myself…we need to be respected, we’re doing a job. I believe in complaints, you know, a complaining family’s a caring
family…Well, you know, when they come in and they yell, and they’re really hostile, and it could be just over little things, and like, I get that, but it makes the staff’s job really difficult (GH).

This staff member went on to explain how he thought it would be helpful to pay more attention to expectations families might have of services to improve their relationships with staff,

I would like to see a change in culture with families…I believe that there should be a bit more respect. I mean I do my best to treat people with respect but in my last couple of houses, I really get this gist that families feel that they can treat the staff anyway that they like, and it really puts pressure on the house…I think there just needs to be that shift of what the families should expect from the organisation, as much as what we should expect (GH).

**Staff Perspectives on Dignity**

Staff felt that having a disability was inherently compromising of dignity and thus heightened the importance of good practice as a counterbalance. One staff member who had a disability herself said rather bluntly,

There is a lack of dignity that goes with my disability, daily I need to ask people to repeat themselves, I can’t hear conversations, miss bits of it, feel like a goose, I feel that I’ve challenged my dignity every day. You put that towards someone who needs to have their bum wiped after they’ve been to the toilet, needs to have their nose blown, needs that level of support, it’s intrusive in every way, shape, or form (EF).

Staff views about the meaning of dignity closely mirrored those of families and fell into two elements, personal appearance and privacy. Similarly too staff pointed to the fine balance between respecting a person’s choices and protecting their public image or saving them from embarrassment. Encapsulating this one staff member said, “you talk about dignity and embarrassment I think it’s sometimes that fine line” (AB).

**Social acceptability - ‘looking so great that people won’t have to stare at them’**

For staff it was important that the people with whom they worked appeared the best they could in public, both in terms of their physical appearance and behaviour. This would help to convey a positive message about all people with disability in general and counter discriminatory community attitudes but to boost the individual’s self-esteem and avoid being
embarrassed in public. Staff said for example,

But I think when you go out in the community… there’s nothing that’s worse…if there’s somebody sitting in their wheelchair, and their wheelchairs are absolutely filthy, that’s the first thing you see about them, you know, and that first thing, people that are still on the verge of maybe whether they’re accepting or not, they’re not going to go, “Look at that guy?”, they’re going to go, “Wow, look at that pig in that wheelchair, see imagine what his home’s like” (AB).

I’ve heard staff say to the person, “Would you like me to help you with that?” like clean that off or fix your hair a little bit better or whatever it might be and then that person can then say, “Oh is it out of place? Well yes, fix it for me, thank you” (CD).

Yet people were sending her out into the public looking like that and I’m saying, “This is really not a good look…it’s a bad look, “Oh, we haven’t got another [headband]”. I said, “Well let’s get in the car, and take her out and get another one…her sister would die if she saw it” (RB).

They always talk about choice in clothing, but I also believe in the dignity… Like we have one girl who is a bit of tomboy and she’ll dress in the easiest daggiest top, because it’s comfy. But if I show her some nice clothing she’ll put that on too and it’s taking that time… People might go, “Oh no, it’s their choice”, and I go, “Let’s offer them some other choices because they really need to walk out the door looking so great that people won’t have to stare at them (GH).

Staff were conscious that their actions in public places could help to avoid potentially embarrassing situations but had to be carefully measured, as these two examples illustrate,

And also, a number of people we support, and I’ve supported in the past are quite prone to inappropriate comments…quite often, through working with them, you can know…you can see where a conversations going to go, they’ll be having it out in public, and you can interject, and not let them come out with the outlandish statement, things like that, that puts ridicule on them, and undermines their dignity (CD).

You’ve got to give it a go to try to get people to use manners, because we’re teaching people how to be out there in the community and that’s a socially acceptable thing to do is to use manners not just snatch…we are training, to get people to say “thank you”, but, you know, there’s a point where you just go, “Okay, well, next time, we’ll get them to say thank you”, but you never tell, you know, it’s very much a
demoralising someone, and disempowering them (GH).

**Privacy – ‘they don’t feel vulnerable when they’re covered’**

Staff primarily talked about privacy in terms of the sensitive provision of personal care and avoiding people being exposed without clothes. They gave less attention to the privacy of personal details or space than families had done. Staff said for example,

> You really have to remind yourself about dignity, really even if they are females coming in [to the house]. You know best that she’s not wearing clothes to come in here and lock the door because you know her family and she might not want you to actually see that so I think that’s reminding yourself (GH).

> It is very important because a lot of the time you’re working very personally with people, their personal care, and things like that, and to do that and still maintain the person’s dignity. So it’s something we have to think about a lot when there’s little ways that we can always do to think about the person’s dignity and privacy, and that they don’t feel vulnerable, that they’re covered, as much as we can, that their door is shut (CD).

> Well advising them of what you’re doing…Well its things like if you’re doing a personal care with them, you shut the door, and you talk to them, and you tell them what you’re doing, if you have to move them from one room to another in a chair, you cover them up (AB).

**Staff Perspectives on Potential Abuse of Rights Vignettes**

Compared to family members, staff were much more consistent and firm in their views about the vignettes presented for discussion. Like the family members, they provided explanations about why such situations arose and gave alternative approaches that staff might have taken. Unlike families however, they were unanimous that all six vignettes portrayed quite serious abuse of service users’ rights. Staff interpreted vignette one as “staff imposing their own values” (CD), entering into a “power struggle” (RB) and being “disrespectful” (EF). They suggested that if they were present when this type situation occurred they would talk with both the staff member and the service user. One staff member said, she thought the “situation was not serious but would monitor the mentality [behind it]” (GH).

> Staff talked about vignette two in terms of ‘stand over tactics” (AB), “bullying” (GH) and “assault” (CD). Most said that they would report such an incident and thought the staff
member should be fired.

All staff thought the third scenario showed the inappropriate use of restraint and a restrictive practice that posed a threat to the safety of the service user. Many referred to the legislative and policy frameworks that governed the use of restrictive practices, and suggested that the actions described were illegal. Most thought any staff member who behaved in this way should be dismissed.

Similarly staff saw the fourth vignette as behaviour that was “completely wrong” (GH) and should lead to dismissal. Just as most family members had done, all staff unequivocally saw the fifth and six vignettes as incidents of sexual and physical abuse. If they witnessed an incident such as this staff suggested they would take immediate action by reporting the incident to their supervisor, calling the police or asking the staff member to leave the service.

**Staff Strategies to Guide Respectful Practice**

Staff across the different organisations talked about three inter-related strategies they used guide their practice and ensure it was respectful of the people they worked with: 1) using themselves as the point of reference for how they treated people; 2) remembering they were guest in people’s homes, and; 3) leaving their values at home.

**Using self as a point of reference**

Staff thought that bearing in mind, “how we want to be treated ourselves, if we were in the same position” (AB) was a good general rule for their own practice and describing what was expected to new or casual staff. As other staff members said,

Just remember, shower them like you would, if that was you standing there tomorrow, and if you’d keep that in mind, every time you do personal…if you think this could be me standing there tomorrow, how would you support that person?, and I think that’s a really good way of looking at it (GH).

Just assisting, as much as they can to make sure that person’s level of presentation is the same as yourself, like you would put on yourself (CD).

One staff member talked about some training in her organisation designed to assist staff to realise what it might feel like to go out looking socially unacceptable.

We actually gave people a bag of clothes, that were the worst, like pink and white striped tights, and a purple top, and a pair of blue shorts, and we made everybody put
them on, and we said, now how would you like to go out looking like that? (CD).

**Remembering they are guests**

The second guide to practice was remembering that as a staff member “you’re going to visit to their home” (GH). This approach acted as a constant reminder about where the power should lie and that residents were not the staff member’s children or family. They said for example,

> We’re entering another person’s home, and that in itself and of itself should be a respectful relationship. If we had visitors, people, tradesmen, what-have-you, who were entering our house, we would no sooner have a tradesman come in and dictate how our day’s going to transpire. I think perhaps that’s a little bit forgotten, our position in somebody else’s home…that notion of respect is a little bit blurred about people’s actual purpose or position in a residential setting (CD).

I think also the biggest respect is at the end of the day, I’m doing sleepovers, as a staff member, it’s my workplace; and if they want to stay up until 12 o’clock, and watch TV...But then when they come to the next question, of a morning, how am I going to get her up, to go to work, deal with that in the morning (AB).

You’ve got to look at this as when you walk in the door you’re a guest in their home, even though it is your workplace, so you need to dress like you would be if you were visiting someone’s house, you need to knock on the door like you’re visiting someone’s house…(GH).

And so, you know, this is not your home, this is not your family, and they aren’t your families (EF).

It’s their home, we’re working in their home, so as a group the women can vet what values they would like in their home, and we can’t go in there and just take those values away, it’d be like someone coming into my house and going, well that’s no good, you can’t have that’, so, you know, you’ve got to treat it as their home (RB).

**Leaving own values at home**

The third strategy was to deal with the reality that ‘everyone has their own ideas’ or ‘little ways’ and for staff to leave behind their own values so they wouldn’t interfere with respect for those of the people they worked with.

People bringing their own views, ideas of what they want in their life, that they’re
trying to force onto the ladies, like environmentally friendly. Yes, we do have to look after the environment, but enforcing it to where you can’t use a dryer because it’s so bad, and unplugging things, and hiding plugs, and things like that, I think that’s not the spirit, for someone? (RB).

Staff 1. I try when I go into a house to leave my values, it might sound strange, in my car, and I don’t bring them into the house. I think a lot of respect and dignity comes from people’s own values within their own life, and sometimes too many of those values are brought into a house, by the workers. Staff 2. That’s exactly right, ‘let’s go to the movies, oh, yes, there’s a good movie, thanks we’ve got the answer, already, instead of, organising it, ‘anybody want to go to the movies? Oh let’s get the paper, let’s have a look’ (AB).

**Staff Perspectives on What Supports Respectful Practice – ‘we need to keep at it’**

**Strong practice leadership**

Staff talked about the demanding nature of direct support work and the dangers of early signs of poor practice not being dealt with adequately by management. They consistently talked about the importance of strong practice leadership and resultant team work as important in supporting good practice. Referring to one of the vignettes about abusive behaviour one of staff member said,

> It’s not an easy job and you can get a lot of stuff, burnout, staff get stressed, if they’re not supported, if they’re coming to you and saying that this person is stressing you out, then it’s not just that they can’t work with that person, it’s obviously something that’s happening, and if you don’t deal with it, these kind of things happen (GH).

Another staff member said,

> Clients are in there cooking, you know, it’s a big difference, and the only way they could achieve that is knowing what those clients required, in the supports that we were going to provide for them, and for me that is very much about respect, for people with no communication, you know who have no way of telling you, but have learnt through experience of what works, what doesn’t work, and actually living that, every day, as a team. (AB).

Practice leaders in the focus groups talked about how they used supervision and team meetings to pick up poor practice and support staff.
Taking over the dinnertime prep rather than the clients and she stepped in and changed that little bit, by letting them know through supervision and team meetings…So I think it’s that constant vigilance and constant catching up with people, as soon as something happens, I think is how I see thing’s changing (AB).

Often in my supervision we do lots of role-playing… And then even in our team meetings too just talking about what people do…just saying look that they’re doing good when they’re doing good, and when they’re not doing so good, talk about that, and why they’re not, it’s not a good way of doing things (CD).

Some supervisory staff also highlighted the importance of maintaining respect for the staff they worked with through the way in which they handled supervision and ‘that’s not ok conversations’. They said for example,

Being aware of their dignity… and not embarrassing them…if they’re going to learn…then being honest and open about how things are with those conversations you have in supervision (AB).

If you’re telling someone to do something you’ve got to wait until he does finish or you might want to see him first time and if he hasn’t done the job properly then you might have a word with them; not trusting him is like I would say is a lack of respect as well. Yes, staff to staff, and you have got to create the environment in the workplace, which will reflect to the clients (CD).

**Involving service users in staff interviews**

Staff from one organisation talked about the value they saw in the involvement of service users in selection of staff, as this was both empowering for them but also helped more directly to assess whether staff had the right attitude towards people with disabilities. However, they cautioned that if this were to happen, the appropriate level of support should be provided and service users should be paid for their time and expertise. One staff member talked about how she had supported a service user to devise questions for a staff interview,

We discussed them with her and then I put them up on the computer, she cannot read, so we did it in bold writing…“What would you do if I wouldn’t get out of bed in the morning to go to work?”’, and the other one was, “I want to stay up after 10 o’clock in the night time, what would you do?” (AB).
**Reporting disrespectful or abuse practice**

In contrast to family perspectives, the staff discussion of the vignettes suggested they were much more willing than families though to speak out about or report poor practice or incidents of abuse. Most were very clear that their organisation did not tolerate abuse and it was their duty to report all incidents that might be considered as such. One staff member in response to one of the vignettes said,

> I think, I would hope (laugh) that they might ring on-call, and ask them what to do. I think that that’s what I would do is go, “You know, I’ve just seen something, I’m not quite sure of, what do you think” and then, give them the responsibility to take that over (GH).

However, as the comment below suggests some staff were also aware that reporting disrespectful or abusive practice was a difficult thing to do and didn’t always happen,

> I think sometimes a false sense of loyalty to their fellow staff member, so they’re like, “Gee, I don’t want them to get into trouble, oh, they’ll know it’s me that dobbed on them, that time, kind of culture” (CD).

Several staff volunteered examples from their own experience where they had taken action at something they had seen as been unacceptable. One said for example,

> Myself and another staff member were going to pick up a resident from a day program…observed the overuse of physical restraint, right in front of our eyes...not only were we seeing something that shouldn’t be happening to this person it could be happening to our person as well...this person has a right to be protected and we have a responsibility to report this. So we arranged a meeting at that day service…they were gobsmacked when we spoke to them about it (CD).

**Discussion**

**Abstract Concepts in Practice**

This study demonstrates the way abstract concepts such as respect, dignity and the right to be free from abuse are operationalised and applied in the everyday practice of staff in supported accommodation services. It had a relatively narrow focus and accordingly, the portrayal of good staff practice in the findings does not encompass the whole spectrum of rights set out in the United Nations Convention on the Rights of Persons with Disability. In particular little emphasis was given to exploring the application in practice of the right of
people with intellectual disability to full and effective community participation.

The study found considerable agreement between family members of people with intellectual disability who use supported accommodation services and staff in these services. Both groups suggested that respectful practice had five main elements; 1) regarding each individual as their own person; 2) enabling support; 3) sensitivity through interactions and language; 4) taking time to find out, and; 5) navigating complexity. Families suggested a sixth element, staff-service-family collaboration, providing negative rather than positive practice examples of this element. Practice that upheld dignity had two elements that ensured; 1) social acceptability, and; 2) privacy.

With only one or two exceptions both groups of respondents interpreted the vignettes of abuse of rights similarly as the inappropriate use of power and control by staff. Notably however, members of three of the eleven families who participated, almost a quarter, were equivocal in making firm judgments that several of the vignettes portrayed undue exercise of power by staff or disrespectful behaviour. Some families also used what might be considered inappropriate language to refer to their relative with intellectual disability, emphasising their limitations rather than strengths, and illustrating these by drawing parallels with children. Several families referred to themselves, rather than their relative with intellectual disability as the rights holder. This was particularly the case for family members who were the formal guardian of their relative. To some extent this point of view is correct, as Guardianship does strip people with disability of their legal standing.

In many ways the language used by some families reflected the way, until recently, mental age, which tended to liken adults with intellectual disability to children, was used to explain intellectual disability by the ‘psych’ professions. Despite this however, their comments conveyed very similar ideas about dignity and respect to those of other families and staff. Nevertheless their ‘inappropriate’ language might easily give the impression that some families were out of step with current policy directions and human rights imperatives. Taken together these findings suggests that family members may benefit from opportunities to explore further and discuss core concepts in disability policy, particularly in respect of inappropriate use of staff power and the shifts that have occurred in language since their relatives’ were young.

The detailed examples of both good and poor practice for each of the elements of respect and dignity provide some powerful illustrations of the translation of abstract concepts
into practice. These may be a useful aid to training and education for front line direct support staff, families, and others involved in providing support for people with intellectual disability.

**Sixth Element of Respectful Practice – Staff-Service-Family Collaboration**

_Similar perspectives but lack of mutual respect - family members and staff_

There was much common ground between family members and staff. Both groups identified that people with intellectual disability required significant support to exercise their rights particularly with decision making. Families and staff pointed to similar mediating factors and necessity for complex judgments to deal with tensions between respecting choice of a person with intellectual disability and safeguarding their wellbeing or dignity. Both groups were acutely aware that people with intellectual disability could be easily manipulated and often found it hard to make informed decisions, which necessitated weighing dignity of risk against duty of care.

Despite much common understanding of the key concepts in practice, there was a significant gulf between family members and staff and an absence of mutual respect. Neither group appreciated that the other had grasped the complex issues involved in good practice. Family members dwelt on negative practice examples, where their relatives had been manipulated by staff. They implied too, that an unquestioning stance by staff often failed to recognise health or other issues that mediated the exercise of choice. Many families felt disrespected by staff; that their perspectives and knowledge about their relative were not valued and were, at times, actively undermined. They doubted too that staff could be relied upon to report poor practice or incidents of abuse as they were too comprised by loyalty to their team members.

The divide between family members and staff at the frontline was replicated in many ways in the relationships family members had with the senior staff and organisations that managed supported accommodation services. Family members felt disempowered by these organisations which they perceived were defensive and did not pay adequate or timely attention to the concerns they raised about the quality of services. At the next level too family members were disillusioned with the capacity of the disability service system and its watchdog bodies to effectively translate policy into practice and safeguard their relatives’ wellbeing.

On the other hand staff did not appreciate that family members understood the complexity of putting current policy aims, such as choice and control, into practice. They
gave very little credence to families as potential partners in supporting service users or as important sources of information about their relative. Rather, a number of staff talked about the way the stance of a family member could undermine the respect and dignity of their relative.

**Building bridges and constructive engagement**

Since the closure of large institutions in Victoria, policy has paid little attention to the continuing role of families in the lives of adults with intellectual disability who live in supported accommodation services (Bigby & Atkinson, 2010; Bigby et al., in press). Rather, policy has focused more intensively on the rights of adults as individuals and on families primarily in the informal sphere as carers of adults with disability who live at home rather than in services (Pierce, Fyffe, Ilsley & Paul, 2011). Little research has explored the relationships between families of adults who use disability services and staff or organisations that manage services and few initiatives have attempted to guide their working relationships. A notable exception is the recent work of the Disability Services Commissioner (2014), which developed five policy principles to guide engagement between families of adult service users, staff and disability service organisations, and detailed strategies for implementation.

The findings of this study bear out the lack of attention to engaging with families of adult service users, and suggests that families appear to have had diminishing opportunities to be involved in their relatives’ supported accommodation service, with service provider organisations, or to meet with each other to share perspectives. Most of the family members in this study have lived through monumental changes to policy and social value accorded to people with intellectual disability over the past 40 years. Unless they have been active members of family advocacy groups such as LISA, Valid or STAR, they have had few opportunities to share their ideas and dilemmas or grapple constructively with new service directions. This appears a significant gap in the disability support system.

Although family members and staff held common perspectives about respect, dignity and the right to freedom from abuse, and indeed shared common goals about the wellbeing of service users, this study suggests they are more likely to be in conflictual rather than collaborative relationships, and have features of ‘destructive’ rather than ‘constructive’ engagement (Disability Services Commissioner, 2014). Relationships of this nature consume significant emotional energy of family members, and staff time, which might be better used. Greater respect for each other, more constructive engagement and collaborative relationships
were suggested by both family members and staff as one way to build cultures of respect in supported accommodation services. Families in particular suggested the need for greater transparency in the way staff worked and reached decisions. They wanted expectations to be clearer and a greater sense of how staff reached decisions to act, and why they paid little attention at times to family views. Their examples of good practice pointed to the significance of more open communication and ongoing exchange of information between families and services. Significantly, their views echo the principles and some of the strategies proposed by the Disability Services Commissioner (2014) to develop more constructive engagement between families of adult services users and services.

Building bridges with frontline staff will be an important task if the energies and commitment of family members are to be better harnessed in building cultures of respect in services. One way to facilitate this may be initiatives to engage families in a dialogue about respect and dignity which may help in finding a common language to share ideas with staff about the challenges of navigating the complexities of competing concepts. This will require work from both parties, families and staff to better understand and appreciate each other’s perspectives and roles.

It is not immediately apparent however with whom responsibility lies for supporting more constructive engagement between families and services. The Office of the Disability Services Commissioner (2014) has begun to take a lead in this respect and garnered significant interest from a number of disability support organisations. It may well be that one of these agencies is willing to sponsor work that takes forward the newly developed policy principles and proposed strategies for services and families to engage more constructively. These principles require implementation, evaluation and piloting of different approaches to actively engage both staff and family members to build common understandings of each other’s perspectives, develop a common language and hone their negotiation and problem solving skills.

The Potential of Family Members as More Active Bystanders in Safeguarding Service Users

Previous research in Victoria (Bigby, 2008) identified the very limited social networks of many service users in supported accommodation, who have neither involved family members nor anyone other than paid staff as part of their life. This is particularly the case for middle aged and older people who have spent their early years in institutions. Many family members in this study drew attention to this absence for other services users who
shared their relatives supported accommodation services. The fundamental importance to wellbeing of social relationships with others who are independent of service provision and as a protective factor against abuse is well recognised in the literature (Robinson & Chenoweth, 2011).

The examples of abuse and poor practice detailed by the family members in this study and their relentless advocacy for their relatives, illustrates the significance of family members as active bystanders in the social ecology of supported accommodation services. Families continually drew attention to minor as well as major staff actions that ran counter to a culture of respectful practice in services. Indeed both groups of respondents highlighted the cumulative effect of the small and subtle staff practices that build cultures of respect in supported accommodation services. Their views suggest the continuing importance of attention to every aspect of staff practice, ‘that constant vigilance’to ‘pick up that mentality’.

The findings of this study give insights into the potentially negative impact for service users who have no one other than staff involved in their life who is concerned about their wellbeing and can monitor everyday aspect of service quality. Addressing the absence of such social relationships in service users lives should be a priority and key preventative strategy to tackling abuse and disrespectful practice.

In Victoria the Community Visitor Program fills this gap in some respects and plays an important role in identifying issues of concern at the service level. It seems however that involved family members, who are well placed to be active bystanders in respect of all service users in the supported accommodation services they visit are actively discouraged to speak up on behalf of other service users on the grounds of privacy and confidentiality. This stance should be carefully re-examined as it runs counter to the position that it is everyone’s responsibility to identify violence, abuse and neglect, and by implication the small and subtle actions that can culminate in major incidents. However, families appear to have been left out of this mandate. For example the Office of the Public Advocates, interagency guidelines for addressing violence, neglect and abuse (2013) are silent on the role of families, talking only about staff and volunteers. It may require some careful thinking about boundaries and methods of reporting, if families are to be encouraged to be more active bystanders.

Importantly too, their confidence in the responsiveness of the disability service system and avenues of complaints may need to be bolstered before they are willing to take up issues on behalf of others as well as their relative. One potential mechanism might be an ‘on call’ service similar to that available to staff to enable families to report poor practice with
confidence that some follow-up will occur, or a local version of the National Disability Abuse and Neglect Hot Line.

**Strengthening Practice Leadership and Organisational Processes**

Systematic abuse prevention frameworks are concerned with factors in the social-ecology of services that prevent abuse. Increasingly, theory and research points to the significance of organisational structures and processes to staff practices. Value coherence is a key element of normalisation theory, for example, signifying the importance of consistent and coherent values at all levels of an organisation (Wolfensberger, 1998). Research on the implementation of Active Support is providing evidence of the positive impact of frontline practice leadership on staff practice (Beadle-Brown et al under review; Bigby, Bould & Beadle-Brown, 2014). It suggests too that observation by senior as well as frontline managers, rather than reliance on paperwork are the best ways to monitor the quality of staff practices (Mansell & Beadle-Brown, 2012). Similarly research on the culture of good group homes suggests that organisational processes such as recruitment, induction, explicit translation of policy in practice exemplars, peer monitoring and strong practice leadership all contribute to a respectful culture that regards services users positively (Bigby et al., in press).

The findings reflect this evidence about the contribution of organisational processes to good staff practice. Respondents suggested that too little attention was given by organisations to the ‘little things’ that cumulatively made up good staff practice but were overshadowed by major incidents. Both families and staff referred to the importance of coherent values throughout the organisation, and the importance of strong practice leadership that provided support to staff, in the form of supervision, modeling and constant vigilance. Investing in structures and skilled staff that enable strong frontline practice leadership should be a key strategy in developing culture of respect in supported accommodation service.

One of the challenges for practice leaders and others involved in staff training and supervision is finding easy heuristics or reference points for staff to use as a guide to practice. The staff in this study reported three such guides, using themselves as the point of reference for how they treated people, remembering they were guests in people’s homes and leaving their values at home. The first and last of these are somewhat problematic.

Staff in the study cited earlier of culture in good group homes (Bigby et al., in press), similarly used themselves as a point of reference for how they should treat service users. This is generally referred to as the Golden rule - ‘do unto others as you would have them do unto
you’ (Honderich, 1995, p.321). On its own however, it is problematic as the reference point is what the staff member wants rather than the service user. In the earlier study some staff also used what is known as the *Platinum rule* that requires people “do unto others, as they would want to be done by” (Popper, 1945/1962). Applying this rule requires abstract thought about what it would be like to ‘walk in someone else’s shoes’, knowledge of the person’s life and experiences from their perspective. This is much more difficult for staff, particularly casuals, but as both family and staff agreed, ‘taking the time to find out’ is a key element of respectful practice. Given that reports and paperwork are an ineffective method of passing on information to staff in supported accommodation services (Bigby, 2008) providers should be challenged to think about more creative and effective ways of doing this. Digital technology and web based applications such as (mobile me) are beginning to demonstrate alternative approaches.

The idea that staff should leave their values at home is also problematic, given that staff are often employed for their values and their capacity to translate these into practice. It implies too that it is feasible for a staff member to separate their own moral stance or values from their practice or actions at work. This position is challenged by feminist work on the ‘ethics of care’ which suggest that caring activities cannot be separated from a moral orientation towards care; “elements of ‘doing’ and ‘being’ cannot be separated with impunity” (Sevenhuijsen, 2000, p.14). If staff are able to switch off and on their values about social justice and the rights of people with disability to dignity, respect and an equal quality of life it is unlikely these will be fully entrenched their every-day practice. What perhaps might be a better point of reference is for staff to leave their own culture, preferences and lifestyle at home, as it these that they need to avoid imposing on service users, if they are to be ‘their own person’.

The somewhat contentious nature of two of the three guides to their practice alluded to by staff in this study suggests the need to reconsider their simplicity and applicability. Further work should be undertaken to develop guides to practice that can capture in simple terms the core elements that drive good staff practices. The elements of respectful practice and dignity identified in the analysis of this study provide some of the ground work for such an endeavor. As has been suggested elsewhere, work from an ethic of care perspective, may provide a useful guiding lens (Rummery, 2010). For example, Fisher and Tronto’s (1990) four dimensions of care (caring about, caring for, taking care of and care receiving) reflect value positions (attentiveness, responsibility, competence and responsiveness) which if
thoughtfully unpacked and explicated could be very applicable to the work of staff in supported accommodation services.

Conclusions and Recommendations

The six elements of respectful practice identified were: 1) Regarding each individual as their own person, ‘it’s his life’; 2) Enabling support, ‘supporting them to achieve’; 3) Sensitivity through interactions and language, ‘the way we speak; 4) Taking time to find out, ‘so you’ve really got to read’; 5) Navigating complexity, ‘none of these things are clear-cut’, and 6) Staff-service-family collaboration, there’s discussion about what I think’. The two elements of practice that upheld dignity were: 1) Social acceptability, ‘looking great’, and; 2) Privacy, ‘just knock’. These elements reflect many aspects of established person-centred practice approaches, particularly Person-Centred Active Support (Mansell & Beadle-Brown, 2013). However there are few practice frameworks available to disability service organisations aimed at front line staff that articulate all these aspects of respectful practice or provide guidance to staff about expected practice with people with intellectual disability. One of the challenges for practice leaders and others involved in staff training and supervision is finding easy heuristics or reference points for staff to use as a guide to practice. Two of the three heuristics, that staff in this study reported using (using themselves as the point of reference and leaving their values at home), are somewhat problematic. The detailed examples of both good and poor practice for each of the elements of respect and dignity in this study provide powerful illustrations of the translation of abstract concepts into practice.

Recommendation 1. A guide to respectful practice for front line staff that includes some easy points of reference be developed from the data collected as part of this study.

Reflecting the focus of systematic abuse prevention frameworks on factors in the social-ecology of services, recent research and the participants in this study identified the positive influence of strong practice and organisational leadership on the quality of front line staff practices.

Recommendation 2. Investing in structures and skilled staff that enable strong frontline practice leadership should be a key strategy in developing cultures of respect in supported accommodation service. As one aspect of this disability service providers should be challenged to think about more creative and effective ways of ensuring all staff, including casuals have sufficient knowledge about service users to enable support to be tailored to their individual needs.
Families and staff have fairly similar ideas about what rights, respect and dignity looked like when translated into practice. Some family members were less certain than staff about what might constitute the misuse of power and control by staff, and thus actions that were potentially abusive. Staff and families did not fully appreciate each other’s perspectives about the complexity of supporting people with intellectual disability to exercise choice and control. This together with the relative absence of strengths based language among some families, and their blunt reference to limitations of capacity potentially gives an impression that some families are out of step with current policy directions and human rights imperatives. However, families have had few opportunities to share their ideas and dilemmas or grapple constructively with new service directions. This is a significant gap in the disability support system that should be addressed.

Recommendation 3. Opportunities should be available to family members of disability service users for mutual support and or explore further and discuss the core concepts in current disability policy and the shifts that have occurred in approaches, language and values over the past 50 years.

Although family members and staff shared some similar perspectives, their relationships are more likely to be characterised by conflictual rather than collaboration. From the experiences of families, the sixth element they identified of respectful practice, staff-service-family collaboration, was largely absent from services. The importance of this element has also been identified by the Disability Services Commissioner (2014) from analysis of complaints received, which led to the development of principles to form the basis of engagement between services and families. Building constructive engagement, greater respect for each other and more collaborative relationships between services and families of services uses will build and strength cultures of respect in supported accommodation services.

Recommendation 4. A consortium of academic researchers, the Office of the Disability Services Commissioner and disability support organisations should seek funding to implement and evaluate the Commissioner’s guidelines for families and services working together, and pilot different approaches to enabling staff and family members to build common understandings of each other’s perspectives, develop a common language and hone their negotiation and problem solving skills.

Recommendation 5. All service providers should develop a clearly documented approach to working with families of service users that is reflected in organisational processes and
structures. This would provide a framework for families of service users and service providers to individually negotiate, document and regularly review their expectations of each other.

The findings of this study give insights into the potentially negative impact for service users who have no one other than staff who is concerned with their wellbeing or who monitors the service they receive.

**Recommendation 6.** Addressing the absence of social relationships in the lives of service users who have no involved family members, through specific network building strategies, should be a priority and regarded as a key preventative strategy to tackling abuse and disrespectful practice.

Families of service users are well placed to be more active bystanders in respect of all service users in the supported accommodation services they visit, but at present are actively discouraged by staff from speaking out about poor practice they observe in respect of services users other than their relative.

**Recommendation 7.** It should be is everyone’s responsibility to identify violence, abuse and neglect, and by implication the small and subtle actions by staff in services that can culminate in major incidents. The role of families of services users as more active bystanders in supported accommodation services, mechanisms to enable families to report poor practice with confidence that some follow-up will occur should be explored further, and guidelines developed for families that parallel the Office of the Public Advocates, interagency guidelines for addressing violence, neglect and abuse (2013)
References


Disability Services Commissioner. (2012). Learning from complaints. Safeguarding people’s rights to be free from abuse, key considerations from preventing and responding to alleged staff to client abuse in disability services. Occasional Paper 1. Melbourne: Author


