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## **Identifying Good Group Homes for People with Severe Intellectual Disability: Qualitative indicators using a Quality of Life Framework**

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## **Key words**

Group homes, quality of life, severe intellectual disability

## **Running Head**

Quality of life in group homes for people with severe intellectual disability

## **Abstract**

Despite change towards more individualized support, group homes are likely to remain for people with severe intellectual disabilities. As such, the search continues for ways to determine and maintain the quality of these settings. This paper draws on in-depth qualitative analysis of participant observations conducted over 9 – 12 months in seven group homes for 21 people with severe and profound intellectual disability. It explores the conceptualization of good outcomes and support for this group in terms of their quality of life and staff practices. The qualitative indicators of good outcomes for this group using quality of life domains can be used by auditors, community visitors, funders, advocates or family members to guide observation and judgements about group homes.

# **Identifying Good Group Homes for People with Severe Intellectual Disability: Qualitative indicators using a Quality of Life Framework**

## **Introduction**

Group homes<sup>1</sup> for four to six residents, located in ordinary houses, dispersed throughout communities, have formed the backbone of services for people with intellectual disabilities in Australia and the UK since the social policy reforms of the 1970s. In Australia accommodation services account for approximately half of all disability expenditure, \$2, 810 million (Australian Institute of Health and Welfare (AIHW), 2012). The bulk of this is spent on supported accommodation, primarily group homes, which serve 15,130 service users who are predominantly people with intellectual disability (AIHW, 2012). Self-directed and individualized funding mechanisms that are central to current reform of the Australian disability system (National Disability Insurance Scheme Act, 2013) will, in the future, enable development of more diverse accommodation models. Nonetheless, group homes are likely to remain a dominant service model for some time due to the slow speed at which system change is implemented, as well as the financial constraints that will impose a continued necessity for people with higher support needs to pool funds. The profile of group home residents may however change as people who do not need to share support costs move to other forms of accommodation (Bigby & Fyffe, 2009).

Although, as Johnson, Walmsley, and Wolfe (2010) suggest, the intent of disability policy has remained the same, the language of rights has replaced that of ‘an ordinary life’ to describe the purpose of group homes. A different approach to administrative accountability, known as New Public Management, has led to an increased emphasis on service quality and accountability (Hood, 1995; United Nations, 2006). Making judgements about the quality of

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<sup>1</sup> Defined in this paper as small 24 hours staffed ordinary houses,

supported accommodation and resident outcomes is a prime challenge for funding bodies, service users (and their families) and practitioner communities that will only expand as market based reform of the disability system continues (Power, Lord, & DeFranco, 2013).

Quality of life has been widely used as a framework to conceptualize and measure resident outcomes (Schalock et al., 2002). Schalock *et al.* suggest that quality of life requires basic needs to be met and then the presence of life enhancers, such as choice and control, personal development and social inclusion. This international consensus identified eight domains: Social Inclusion, Interpersonal Relationships, Personal Development, Physical Well-being, Emotional Well-being, Material Well-being, Self Determination and Civil Rights. In Victoria, Australia, for example, the State government uses quality of life to describe the overarching aim of group homes, and frames the role of staff as being to promote key domains such as “participation in household and community activities, relationships with other people, decision making skills, and dignity and respect” (Department of Human Services, 2012, p. i). Similarly in the UK, the Valuing People White Paper (2001) and updated in Valuing People Now (2009) draw on quality of life domains when they set out four key outcomes that services should seek to support for people with intellectual disabilities – experiencing social inclusion, growing in independence, experiencing real choice and control and exercising civil rights.

Despite evidence that group homes can support a good quality of life for people with all levels of intellectual disability, post deinstitutionalization research has shown that outcomes vary significantly between services (Kozma, Mansell, & Beadle-Brown, 2009). People with more severe levels of intellectual disability are found to have consistently poorer outcomes than people with milder levels of impairment. This reinforces the close link between staff practices and outcomes for those with higher support needs highlighted by Mansell and Beadle-Brown (2012). For example, provision by staff of facilitative assistance,

an approach known as “active support” or “person-centred active support” has been shown to increase quality of staff support and levels of engagement of people with severe intellectual disability, effectively compensating for the disadvantages of a high level of impairment (Mansell & Beadle-Brown, 2012).

The high level of abstraction in policy documents can mean that expected outcomes for people with more severe impairment are difficult for staff to grasp. The “inadvertent trick [that] takes place where the least impaired people are used in the imagery to stand for all the others”, compounds this difficulty (Burton & Kagan, 2006, p.305). Several Australian studies suggest staff struggle to accept that imperatives such as community participation are applicable to people with severe intellectual disabilities, and that they have difficulty translating abstract concepts into concrete expected outcomes that can serve as a guide to their every-day practice (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Clement & Bigby, 2010; Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012).

Moving away from the group home model itself, research has begun to focus on service implementation and the influence of organizational culture, structures and processes on staff practices and consequently on resident outcomes (Mansell & Beadle-Brown, 2012; Mansell, Beadle-Brown, & Bigby, 2013). This paper analyses findings from two studies that are part of an ongoing program of research examining the influence of culture and other organizational factors on staff practices and resident outcomes in group homes for people with severe and profound intellectual disabilities. The first study *Making life good* used qualitative methods to identify five dimensions of culture in group homes (Clement & Bigby, 2010; Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012):

1. Alignment of power-holders values: (*with or against the organisations values or general good practice*)

2. Regard for residents - *Like us (respectful) or not like us (not treated as an equal being)*
3. Perceived Purpose – *doing/caring for or enabling*
4. Working practices – *staff or person-centred practices*
5. Orientation to change and new ideas – *enthusiasm or at least acceptance versus resistance*

In the *Making life good* services, it was found that there was a misalignment with the organisation's espoused values and staff often said 'We're not going to do it that way'; There was a sense of otherness – these people are "Not like us"; Staff very much were seen and felt their job was to be doing things for people - 'We look after them'; rather than enabling them; the working practices were clearly staff centred – we 'Get it done so we can sit down and take a break'; and finally there was resistance to change – "Yes but...". The impact of these cultural dimensions on group home residents was a lack of engagement, community participation, choice and personhood and in some respects comparisons could be drawn between the culture in these services and that of institutions. Given the relatively poor resident outcomes in terms of quality of life domains, we referred to these as *underperforming* homes (Clement & Bigby, 2008; Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012).

The second study *Ordinary life*, aimed to examine the culture in *good* group homes, and compare it with that of *underperforming* homes from the *Making life good* study. Following a similar approach to other studies to locate examples of *good* services, (e.g. Emerson et al., 2001; Clement & Bigby, 2012), we placed an advertisement in the newsletter of the peak organisation for disability services in Victoria that asked readers, "Do you know a group home for people with severe and profound intellectual disabilities that you regard as being one of the best of its kind". We also sought advice about particularly good group

homes from the Community Visitor program, whose volunteers visit all homes for people with intellectual disability in the State of Victoria. Most of the organisations and individuals that responded to our request nominated homes that served people with milder levels of impairment, reflecting perhaps the difficulty of identifying what constitutes good outcomes for people with more severe impairments or perhaps a lack of understanding about how severe intellectual disability is defined. After preliminary visits to the nominated homes, four group home services from three organizations were invited to participate in the study.

The subsequent fieldwork for the *Ordinary life* study found differences among these four homes that suggested they were not all as *good* as had been anticipated. Therefore, before making claims about cultural differences between *good* and *underperforming* group homes it was important to establish a sounder basis, than reputation and views of disability service providers or community visitors, that the homes in the *Ordinary life* study were indeed *good* and led to expected quality of life outcomes for residents.

The question of what constitutes a *good* group home, and what such a home looks like when it serves people with a more severe level of intellectual disability is important in its own right. As discussed earlier, judgements about service quality will be increasingly left to service users and their families in new market systems. In turn they are likely to be reliant on the views of others, the way services portray themselves or are advertised. An important question then is how the self-reported views of organisations and the perspectives of others, in this case, staff and community visitors, about which homes are good or ‘the best of their kind’ align with results of systematic investigation. With this in mind, one aim of this paper is to compare data about group homes drawn from two studies (*Making life good* and an *Ordinary life*) to see whether those nominated as good or the ‘best of their kind’, have resident outcomes and associated staff practices that lead to a good quality of life for residents.

Determining what constitutes a *good* group home, and whether a group home that serves people with severe impairments can be considered *good* has significant challenges. As reviewed by Mansell and Beadle-Brown (2012), a wide body of research using structured, direct observation has demonstrated resident outcomes are often inextricably connected to staff practices. Mansell and Beadle-Brown also commented that staff practices are particularly nuanced, manifesting in different ways from those for people with mild intellectual disability. For example, choice or control may occur through momentary interactions between staff and residents (Reinders, 2010) or the depth of interpersonal relationships may only be evidenced by moments of fun or comedic routines (Johnson, Douglas, Bigby, & Iacono, 2012). Few quantitative measures used in large scale survey research capture such nuanced exchanges and they are often poorly attuned to people with severe or profound intellectual disabilities. Most rely on staff or self-report, the former of which can be subject to a halo effect and the latter not applicable to people with severe or profound intellectual disability (Mansell, 2011). As the benchmarks used in many measures do not take account for the potentially reduced capacity of people with more severe intellectual disability for participation or engagement or of their inherent limitations in self-determination and decision making, this group invariably scores poorly on these dimensions.

Mansell (2011) argues that observational methods are critical for measuring the lived experience of people with severe and profound intellectual disabilities. The observational measure of Engagement in Meaningful Activity and Relationships (EMACR) combined with the Active Support Measure (ASM) (Mansell, Elliot, & Beadle-Brown, 2005) is one of the few that uses observational techniques to measure the frequency, duration and quality of interactions between staff members and residents as an indicator of resident engagement, and for which comparative data exists for people with severe intellectual disabilities living in a wide range of settings in the UK and in Australia (Mansell & Beadle-Brown, 2012). However

these measures are based on a two-hour observation usually collected leading up to the evening meal. Although such measures have been found to be representative of other points in the day in terms of the time people spend engaged (Mansell & Beadle-Brown, 2011), they are none-the-less, like most quantitative measures, a snapshot of a particular point in time and provide little evidence about the variety and consistency of support and the outcomes for people over a longer period. As people with more severe intellectual disability are likely to be supported by approximately 10-12 staff who are rostered over 24 hours seven days a week, variation and lack of consistency is common, especially in houses where staff focused rather than person-centred culture exist. Analysis of in-depth qualitative observational data collected over an extended period, during different days of the week and times of the day is one method that overcomes some of the shortcomings of quantitative methods.

The analytical process used to compare the homes in the two studies and substantiate or otherwise the claim that the *Ordinary life* group homes nominated as the best of their kind were indeed *good*, provided the opportunity to address the poor articulation, in policy and practice documents, of the nature of good quality of life outcomes and associated staff practices for people with severe impairment. Developing indicators of these elements will contribute to staff, supervisor and wider organizational understanding of abstract policy intentions. Indicators too are the first step towards development of an observational or audit tool for monitoring quality of group homes and providing reliable information for prospective group homes service users and their families.

This paper has three aims:

1. Using a quality of life framework, to compare resident outcomes and staff practices in seven group homes (four of which were nominated as the best of their kind, from the *Ordinary life* study and the other three found to be *underperforming*, from the *Making life good* study;

2. to explore whether the outcomes and staff practices in some or all of these homes could be described as consistently *good* across staff and over time during the 9– 2 months of participant observations, as well as across all quality of life domains; and
3. to develop a set of qualitative indicators and illustrative examples that translate abstract concepts and expectations into concrete examples of expected good quality of life outcomes and associated staff practices for residents with more severe and profound intellectual disabilities.

### **Method**

The data reported were drawn from the two studies, *Making life good* and an *Ordinary life* both of which used participant observation to collect ethnographic data over an extended period about staff practices in group homes. In addition these studies used some descriptive measures of participant characteristics. The methods used in these studies have been reported in detail elsewhere (Clement & Bigby, 2010; Bigby, Knox, Beadle-Brown, & Clement, in press), but a summary is given below.

#### **Participants and settings.**

*Sample 1: Making life good:* Three group homes each of which had four to six residents with severe intellectual disability giving a total of 16 residents.

*Sample 2: an Ordinary life study:* Four group homes, each of which had four to six residents, some of whom had severe and profound intellectual disabilities, giving a total of 21 residents.

The houses in both studies were staffed 24 hours a day and operated under similar State government policy and regulations, in Victoria, Australia.

## Measures.

### *Resident characteristics.*

In order to check that the people being supported by the homes had more severe levels of intellectual disability, data about residents were collected using the short version of the *Adaptive Behavior Scale* (Hatton et al., 2001; Nihira, Leland, & Lambert, 1993); the *Aberrant Behaviour Checklist* (Aman, Burrow, & Wolford, 1995); an item on ‘quality of social interaction’, originally from the *Schedule of Handicaps, Behaviour and Skills* (Wing & Gould, 1978); and a modified version of the *Observed Secondary Health Conditions* (OSHC) questionnaire (Koritsas & Iacono, 2011). These measures were completed by a key informant who was usually a staff member with a good knowledge of a specific resident.

### *Participant observation.*

In summary, visits were made to each house over an extended period of 9-12 months, including all days of the week and spanning most times during the day, during 2010 and 2011-2012 respectively. An average of 22 visits of three hours duration were made to the four *Ordinary life* houses, and an average of 12 visits of six hours duration to the three *Making life good houses*. Observations were unstructured and focused on staff day-to-day practices whilst on shift and in staff meetings. Detailed field notes were written after each visit. In addition documents about organizational structure, policies and procedures were reviewed as sources of information about the ‘organizational life’ (Forster, 1994). Semi-structured interviews were conducted with each staff member and with consenting family members across all the houses. All data were collected by the first author or a research fellow skilled in this method of data collection.

## **Ethical approval.**

Both studies were approved by La Trobe University human research ethics committee. Consent was gained from group home staff. In accordance with the Australian National Health and Medical Research Council Ethical Guidelines (2007) consent was sought from the legal guardian or next of kin for all residents as they were judged not to have the capacity to consent for themselves. All names used in this paper are pseudonyms.

## **Analysis**

NVIVO 9, qualitative data analysis software, was used to support the analysis and manage the large volume of data. A template analytic approach was used to analyse the data (King, 1998) which for the purpose of this paper were categorised under quality of life domains and coded in terms of good or poor examples of outcomes or practice on each.

### *Development of qualitative and quantitative indicators of quality of life.*

Schalock et al.'s (2002) quality of life domains were used as the conceptual organizing framework. The coded qualitative data were extracted and used to adapt indicators for each domain to more accurately reflect the outcomes and associated staff practices commensurate with a good quality of life for people with severe and profound intellectual disability. As shown in Table 1 this enabled the domains to be recast to reflect the life activities significant for this group of people and take into account that in all areas of their lives they require support to achieve outcomes.

<Insert Table 1 about here>

In accordance with well-established processes for translating qualitative data into a quantifiable form, a four-point scale was created to quantify the qualitative data and rate how each group home fared on each of the quality of life domains (Miles & Huberman, 1994); 0 =

outcome was not present for any residents; 1= mixed outcome, partial or strong outcomes for some residents some of the time, 2 = partially good outcome for all residents most of the time, and 3 = strong outcome for all residents most of the time.

As indicated, this scale reflects the proportion of people in the home who were achieving each quality of life domain and how consistent this was. If the indicators outlined in Table 1 were all present for everyone then the home would have received a 3 for that domain. If none of them were present for anybody then it would have been a 0. If only some of the indicators were present or if they were only present some of the time for some of the people then that would have been a 1. A rating of 2 would have meant the indicators were mostly present or achieved for most people.

Although the ‘unit of analysis’ was the group home, scores of 2 and 3 required that all residents in a setting were achieving the quality of life domain at least to some extent, a *good* group home should produce good outcomes for all its residents not just some. The scoring process involved the first and second author reviewing the qualitative data from both studies and determining a score for each domain in each house. Initially the scoring was done independently by the first two authors, and then followed by discussion of the rationale for each score and moderation of differences. A further process of moderation was undertaken with the third author who was less familiar with the data and drew upon a selection of coded transcripts from each house rather than the full data set. The resultant scores reflect an ordinal level of measurement, as the distance between the categories on the scale is not equal but does enable comparison of the homes on domains and for them to be ranked.

## Findings

### Participant and setting characteristics

<Insert Table 2 about here: summary of resident characteristics>

As can be seen, there were some differences between the *Ordinary life* houses and the *Making life good* houses, in terms of sector, length of time established and some of the characteristics of the people served. The government services in both studies were generally supporting an older population than the non-governmental services. There was a range of resident level of ability within all settings and although not directly comparable across the two samples, those supported in three of the four *Ordinary life* houses had mostly severe to profound intellectual disability and other complex needs – such as physical disabilities, communication difficulties.

On the OHSC questionnaire, across the four *Ordinary life* houses, the mean number of mild to chronic health conditions was 7.8, out of a maximum of 15. When considered in conjunction with the ratings for level of impairment, a number of residents in *Hesta Avenue*, *Tiger Street*, and *Bee Lane* can be described as people with profound intellectual and multiple disabilities.

### Ratings for quality of life domains

Ratings for each home are presented in Table 3. Given the descriptive nature of the indicators and word limitations, rather than present illustrative data in both Tables, we have drawn on exemplars of good quality of life outcomes and associated staff practices from each domain to discuss the comparative scores, with specific reference to the residents with severe

and profound intellectual disabilities. For domains where scores were low, examples of poor practice are also provided.

<Insert Table 3 about here>

Table 3 shows a differentiation between underperforming *Making life good* homes and the reputedly good *Ordinary life* ones. It illustrates that the latter homes were not strong across all domains, suggesting they were not as good as they were reputed to be. Described below is both an indication of how each domain was coded from the participant observation data and examples of good quality of life outcomes in each domain.

### *Emotional Well-being*

This domain required judgement about resident well-being and their overall satisfaction with life based on interpretations of frequency and tone of residents' behaviour, body language, facial expressions, and vocalisations. Satisfaction is not a constant state, but ebbs and flows, and expression of dissatisfaction at times may help to ensure needs are met (for example that a person is cold, hungry, wants to be moved and so on). As people with more severe intellectual disability have more chronic health conditions, ill-health and disability does not necessarily equate with dissatisfaction. The absence of unhappiness or challenging, oppositional or defiant behaviour might be taken as a sign of well-being, together with the smiles and laughter.

Much of the evidence about emotional well-being stemmed from social interactions between residents and staff or family, many of which involved social touch or joshing, or from enjoyment of activities initiated by staff as these examples illustrate.

Bruno arrives a few minutes late for his shift and comes over to see Seth. He talks to him and rubs his rib-cage affectionately. Seth seems pleased to see him and vocalizes loudly. (Hesta Ave)

Delta comments that Jake is in a lovely mood. Whilst we have been sitting in the café he has smiled a number of times. Jake moves his hand towards her. He wants a 'love snuggle' she says. She tells me that sometimes he pulls her hair in trying to achieve this.....She takes his hands and he touches his lips to her cheek. 'I'm glad you're so happy' she says. (Tiger St)

Severity of their impairments meant few people displayed seriously challenging behaviour but dissatisfaction was expressed through low intensity defiant and oppositional behaviour towards staff. In several of the homes rated low, particular residents were singled out for less favourable treatment or regarded as a nuisance.

#### *Interpersonal Relations*

None of the houses rated strong on this domain, as few residents had more than a passing acquaintance with people other than staff and family members, and most had little interaction with their co-residents. One notable positive exception was Hank's relationships with an elderly couple which appeared to have grown into friendship which was described by a staff member;

There's an elderly couple down the road, we help with their garden and just go down and say hello. They're great, they always come up and say hello to Hank and talk to him and you see the response in Hank (Hesta Ave).

Three houses were rated as partially strong on the basis of staff support to enable residents to have positive contact with family and consistently warm respectful staff interactions with residents. In these houses staff proactively supported residents to stay involved with parents and extended family members, and enabled families to feel comfortable and involved in the household as these field notes indicate.

Madge supports Beth to make some telephone calls. She first picks up the answer-phone message... She points to another name in the Filofax and ends up talking to David (nephew) and his partner Mary. (Hesta Ave)

Ivan's sister is having a baby, due any time soon. Zadie [staff] wants to be notified when the baby is born, so that she can come in and take Ivan down to see his new niece or nephew. (Tiger St)

Zara's parents told me that they had also visited on Sunday. ... The lounge room was 'cleared out' for the three of them, although there was some people traffic through the lounge. Zara's wheelchair was moved over to the settee, which Mrs Collins sat on for some of the time. Eliza [staff] also came and spoke to the parents for some time. (Bee Lane)

Staff played a very significant part in residents' lives. The examples show a significant overlap between the two domains of interpersonal relationships and emotional well-being, as in many instances it is during the positive, warm and respectful interactions with staff that the residents visibly expressed satisfaction. The field note extracts below, which record the words and actions of staff provide exemplars of staff practices that led to good interpersonal relationships with residents.

You have to talk to the guys, and be friendly, and don't treat them like they're not there.....they're not left alone, people talk, even if they haven't got language skills, you still talk to them, there's just that humanity aspect of it. ...the residents like to socialise with us, they like to be where we are and do what we're doing. (Bee Lane)

The journey to the mall is about 25km. He gives a running commentary for Seth about what he is doing. 'I'm having to pull in to the inside lane. I've got some speedster on my tail.' A van goes by advertising a *Segway* on the side..... He tells Seth what a

*Segway* is. He tells Seth that he seems excited and after a '1-2-3' they both holler.

(Hesta Ave)

The positive affect, fun and what may be seen as joyous or upbeat interaction between staff and residents was missing in homes that rated low on this domain. These homes had a cheerless climate; interactions were functional without the use of social touch, or evidence of committed relationships and emotional bonds between staff and residents. Relationships were functional and stayed clearly within professional boundaries posing no challenges to the fine and often debated line between friendship and worker client relationships (Reinders, 2010). A sense of the different climate between homes on this domain can be gained from these two comments by supervisors.

And I think they're all quite comfortable, because there's no behaviours, so I'm sure they're all calm, and so yes, so I think they're on a good wicket, they're enjoying it.

(Apollo Drive).

We try and bring a sense of joy into the house, music, happiness, so that whatever happens, and whenever it happens, when you've been there you've provided the best that you could provide on that shift. (Bee Lane)

In Apollo Drive and the *Making life good* homes, some staff interactions with residents were disrespectful, and a firmer delineation existed within the house between staff and resident in terms of space and artefacts which tended to reinforce an 'us' and 'them' stance.

### *Material Well-being*

Indicators in this domain focused on residents having their own personal possessions, sufficient resources from private income or state benefits to reside in a home adapted to their needs, and use of discretionary funds to purchase items or experiences based on personal choice such as holidays, massages, food, clothing and music. Personal possessions stem not

only from support to make purchases but also to take photos or organise displays of other items reflective of individual tastes, such as posters or sports memorabilia. Bee Lane which rated lowest of the *Ordinary life* homes on this domain was an older smaller home less well adapted to residents' needs which meant two residents shared a room. One resident missed out on externally purchased luxuries, as the supervisor said "some residents also get a massage once a fortnight, except Tess as she cannot afford it". Homes across both studies had access to their own private and adapted transport mainly in the form of six seater buses. The three top ranked homes were purpose built, well adapted to residents needs and residents had personal possessions in their rooms and around the house together with sufficient resources to access holidays or other luxuries of their choice. Examples are found in the comments of staff and observations in the field notes;

Making sure that all four women have an annual holiday is a goal here. All four residents have had a holiday during the research period (Apollo Drive).

Cain was a resident who has additional visual and auditory impairments. Inside his bedroom, running along the wall, is a hand-made sensory artefact. It is Cain's name made in foot-high letters, covered in shells and buttons. Above it are photos of Cain with his mother and father ..... Next to the heater is a portrait of Cain as a young man, painted by his father. (Tiger St).

### *Personal Development*

The focus of this domain is on supporting engagement, and involvement in an expanding range of activities that enable residents to experience choice, success and satisfaction. Increased skills and independence are also an outcome but are not the primary focus. Rather the aim is provision of the right amount of support for residents to be engaged, not necessarily carrying out tasks independently.

The *Ordinary life* homes did not operate a hotel model in the same way as the *Making life good* homes but nevertheless did not rate as having strong outcomes for all residents on this domain as support for engagement in meaningful activities was not a consistent feature of staff practice. In Apollo Drive, for example, skill development was emphasized, and residents were supported intermittently though somewhat mechanically to be involved with domestic tasks or leisure activities such as beading. As the extract below illustrates not all staff complied with the emphasis placed on active support by the supervisor;

The supervisor told Grace and Candy that the house is an active support house. ...He did admonish Grace for drawing the curtains and told her that they get the ladies to do it. She later washed up the pans, after the supervisor had gone, and wasn't given direction by Pansy [an experienced staff member]. (Apollo Drive)

The field notes below give good examples of support for engagement and extending residents' experiences illustrating how this occurred inside the home and community places.

Jake and Effie stay in the water for 45 minutes. For that time they stay close to one another. Effie is very proactive in interacting with Jake, talking to him, pulling him about the pool, pointing to another part of the pool where they should go to, getting him to hold on to the metal rail. (Tiger St)

Pearl pushes Seth down to the laundry. She opens the tumble-drier and puts the clean laundry on a table, which is in the middle of the room. She puts a doona<sup>2</sup> cover that has the faintest bit of heat on Seth's lap and folds up the other items. She gives Seth

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<sup>2</sup> Australian, a quilt, stuffed with down or a synthetic material and containing pockets of air, used as a bed cover in place of the top sheet and blankets Also called: duvet, (UK) or continental quilt

two flannels, one at a time, and instructs him to put them on a trolley that is next to the wheelchair (Hesta Ave).

One supervisor captured the importance of expanding the repertoire of activities in which residents might be engaged when she said, “we just keep trying things and if she’s smiling we figure she must be having a good time”. This was also illustrated in interviews with other supervisors who said;

Fawn doesn’t like crowds, for many years she was never taken to shopping centres, she was never taken to stage shows, we started taking her to more low-key, high school concerts or local performances. She likes the music but she didn’t like the crowd, once she was more comfortable in the crowds we started taking it further and further, and now she will attend a live show, in the city. (Tiger St)

Tess might say no to really everything, but with coaxing, she’ll say ‘no, no, no’ but then she will do things. It’s like with the shopping. ‘No, no. no. no’, but now just loves it. With her we just need to push her a little bit further to try things and then if she goes ‘No, no, no’ well then okay that’s fine. (Bee Lane)

The reality of the phrase from active support that every moment has potential is clear in the first extract below, while the second illustrates the type of inconsistency in staff support that was evident even in the more highly ranked homes which meant they rated 2 instead of 3 on this domain.

Adele supports Edie so that she can do some of the task for herself. Adele loads the spoon with pasta and sauce. When Edie opens her mouth, Adele quickly transfers the spoon to Edie’s hand, who puts the spoon in her mouth.... (Hesta Ave)

Tess asks for a drink and Golda fetches her a glass of water. ‘Help me’ she says. Golda prompts her to drink the water herself. Golda prompts Tess to hold the small cloth in her left hand. (Often other staff will hold this to her chin to catch any

spillage.) Golda gives lots of reinforcement. ‘Yeah you’ve got it’. ‘All on your own, well done’. (Bee Lane)

The high demand on staff time to meet resident’s personal care needs that could take them away from supporting engagement was actively managed in one house by the process of ‘setting up’ residents with preferred passive activities such as listening to music or looking out a particular window. It was however, difficult to judge whether residents were engaged or not in these activities, as illustrated in the field note below.

She wheeled Pete into his bedroom. A while later I go into see him. He is listening to ‘They could have been champions’ and appears to be laughing at a song about the Richmond Tigers always finishing 9<sup>th</sup>. (Bee Lane)

Another practice that occurred most commonly in the three more highly ranked homes was engagement of residents in social interaction whilst staff did domestic activities, which arguably residents could have been more engaged in. This meant opportunities were lost not only to promote personal development in terms of skills and experiences but also the types of non-verbal interaction that happens naturally as part of supporting someone to take part in an activity.

...the socialization side of it takes up a lot of your time, especially with Vera and Tess, and Pete, .... and we still feel like we don’t give them enough time, enough one on one, ...but you’re always talking to them, you’re always interacting. (Bee Lane)

### *Physical Well-being*

The indicators in this domain reflect the high level of personal care and attention to other health needs required by this group of residents. Indicators emphasize a personalized and respectful manner in providing care, as well as understanding and adhering to individual preferences such as attention to timing, atmosphere and warmth. Important too are the more usual elements of preventative health care and lifestyle factors that affect health, safety of the

physical environment, and prompt and appropriate responses to acute health needs. The *Ordinary life houses* were all strong on this domain, in contrast to the *Making life good* houses where provisions of personal care was a more perfunctory task, carried out in a way that gave little opportunity for personal preferences to be displayed or acted upon. Good exemplars are captured in the extracts below.

Adele prompts Seth to chew and eat slowly. She also refrains from too much conversation with him, having told him that if they talk he won't concentrate on eating. (Hesta Ave)

I talk to the person, tell them what I am going to do, don't just go in there and ... do it...So we'd walk in and we'd say "Hi Fawn, how are you, come on it's time to get up" ... I wouldn't go "Right now we have to put her on the toilet." I help the people here because they're adults, I don't treat them like I'm bathing them or feeding them. (Tiger St)

### *Self Determination*

The limited capacity of people with more severe levels of impairment for independent action means it is particularly difficult for them to exercise autonomy and self-determination. They are largely reliant on staff to present choice, interpret and act on their preferences about day to day rather than larger decisions. For example,

... if you listen to Kloe, and to her yelling at you, there's all different yells, and you'll know, like there's a yell when I walk through the door because she knows I'm here or there's a yell that: "I need to go to the toilet" ...so you need to listen. (Tiger St)

Seth will definitely respond between two objects, like two colours of a tee-shirt or something. Usually, I say, "Do you like this one, or that one?", and I hold it up in front of him (Hesta Ave)

One strong indicator is the extent to which people are not only recognised as individuals but lead individualized lives, reflective of their preferences, rather than group based lives.

Perhaps in this more than any of the other domains outcomes are limited by the depth of staff knowledge about individual residents, and organizational structures and resources. As the two extracts below illustrate the tension between a group and individualized lifestyle was particularly evident in the two lower ranked *Ordinary life* houses where a group orientation to support was evident for much of the time, characterized by routines, set menus, meal times, and attendance at day programs. This compared to the flexibility, individualized meal and bed times, and attention to resident rather than staff needs in higher ranked homes.

For Pete at one stage he wanted to go to the football on a regular basis ... we didn't actually follow through with that... So he gets to go occasionally now.... but the actual going every Saturday we couldn't due to resources, money, and fairness to the other guys (Bee Lane).

The guys will tell us when they're ready to go to bed. ..I don't actually have a stiff routine because people think routines can't be deviated from, so they're guidelines, 'It's usually around this time that Reba might look tired and may want to go to bed', but Reba will walk into her bedroom if that's the case. If not, she'll walk up and go into the tele-room and she could sit there until one or two o'clock until she's ready to go to sleep and that's her choice and that has to be respected (Hesta Ave)

The positive effect of individualized funding packages enabling less routinized day support was also evident for several residents in one home. For example,

We know a few things that we're absolutely sure Jake likes, so we incorporate his swimming and his outdoor activities; walking, going to parks, and things like that. We listen to Jake to make his life fulfilling and happy. If he doesn't want to do something,

we don't do it. I think that's the beauty of an individual support package..... he has the choice to do whatever he wishes, as well as a bit of structure (Tiger St)

All the *Ordinary life* homes had processes in place for development of person centred plans, though these were not always well monitored or current.

A document called, 'Brief summary and my personal profile' contained individualized statements about how to support the residents. For Edie, one read, "Turn on bedroom light in the morning and let Edie wake herself. Do not try to walk or stand Edie if she is not fully awake". (Hesta Ave)

### *Social Inclusion*

The indicators on this domain focus beyond community presence and the use of community places to taking part in the range of activities that occur in the community. These may be participation in community organizations or neighbourhood activities or transactions in shops. Indicators include support to be recognized or known by others or having valued roles. Participation in segregated activities in community places can be important in the formation of friendships but were judged as needing to occur in conjunction with more individualized non segregated opportunities to gain a strong score on this domain. Examples of good outcomes and associated staff practices are given in the excerpts below.

Ivan goes to a hairdresser, and the hairdresser now knows him, and so every time Ivan goes in there they notice: "Hi, Ivan, how are you"... (Tiger St)

They have the supporters' club, in the club rooms, and there's an afternoon tea and a raffle so he loves going in there and sometimes he gets to draw the raffle, but it's not like: "Oh, Seth's here, he can do the raffle", it's no big deal, it was just: "Oh, Seth, you're here today, do you want to do the raffle today?" ... And while we're walking

round the ground, people are just saying: “Hi, Seth, how’re you going”, you know just like they would with anybody. (Hesta Ave)

All the *Making life good* houses struggled to support anything beyond community presence for residents (Clement & Bigby, 2010). Similarly, the lower ranked *Ordinary life* homes predominantly supported residents to participate in group based or segregated community activities, which tended to be restricted to weekends.

### *Rights*

In many ways all of the domains can be seen through a rights lens, and the indicators are broadly focused on residents being treated with dignity and respect in all aspects of their lives, having access to all parts of their home and the community and a clear articulation of a rights approach by staff in their practice.

Venus, the manager at Tiger Street, said, “I don’t see their disability any more, I see them as people, you know. I don’t see Kloe sitting in her wheelchair. Out in the community, I see her dressed, a lovely lady, enjoying the community, dressed beautifully.”

This domain includes exercising citizenship or having a say, which to be meaningful rather than tokenistic for people with severe and profound intellectual disability may diverge from the usual expectations of voting, participation in advisory structures or lobbying. For example, Hank, was paid \$400 for his part in filming a community education video. Seth was a member of the organizations consumer group, and although it was unlikely he understood the proceedings, he clearly enjoyed being part of the meetings, and it might be argued his presence was an important reminder to the group about diversity.

Only two of the *Ordinary life* homes had a strong rights discourse, reflected in organizational documents, procedures and processes for assessing and monitoring resident rights. For example,

One of the questions in the Human rights checklist is ‘Can I choose who looks at my file?’ ..I ask Grace whether she knows where Niki’s diary is. She involves Niki in my request, asking her whether it is alright for me to look at the diary, and whether we can go into her bedroom. She pushes Niki into her bedroom to fetch the diary and finds it in the chest-of-drawers (Hesta Ave)

The third aspect of this domain was having others both inside and outside the service system who act as advocates for their rights. The comment by a staff member that ‘I feel that sometimes the families actually override what the person wants.... I challenge it sometimes, but always involve the more senior management’ illustrates potential importance of having an independent advocate or at least having advocacy roles taken by both family and staff members as a way of opening up space for discussion about what might be the right interpretation of a residents preferences or in their best interests.

### **Discussion**

This study compared the resident outcomes and associated staff practices in seven group homes that had been found to be either *underperforming* or were reputedly the best of their kind, by transforming qualitative into quantitative data, using a 4 point scale. The ratings indicated differences in resident outcomes and staff practices between the seven homes and showed that the four *Ordinary life* homes as a group cannot be considered to be uniformly *good*. Rather the top ranked two homes might be seen as *better* than the others (on the basis of their strength on 6 of the 8 domains), the next ranked two as partially *good* (ranked as strong on 3 and 2 domains respectively). The *Making life good houses* did not rank as strong as the *Ordinary life houses* on any domain which confirmed prior judgements of these houses as *underperforming* based on qualitative data (Clement & Bigby , 2010).

Neither of the *better* houses performed strongly on the domains of personal development and interpersonal relationships. The first of these is closely associated with

person centred action and the practice of active support, whereby staff provide sufficient facilitative assistance to enable people to engage successfully in meaningful activities and social relationships (Mansell & Beadle-Brown, 2012). In these homes, social engagement and the provision of warm and respectful personal care took a slight precedence over assistance to engage in meaningful activities. This was most evident in Bee Lane, which had an exceptionally strong ethos of warm and respectful relationships, where the notion of care clearly outranked that of support (de Waele, van Loon, van Hove, & Schalock, 2005). Nevertheless, although rapport and interaction with staff was high in the *better* services, most of the communication was verbal and beyond the comprehension of the residents. Heavy reliance was placed on context to help people understand what was happening, and active listening (Dennis, 2002) to interpret preferences. Relatively little use was made of communication aids such as switches, pictures, and objects.

Our rating scale was based on the judgement of greater potential for resident engagement in meaningful activities. Although less prevalent than expected, a recent UK study of skilled support for people with severe or profound disabilities and complex needs found a strong association between good active support and other person centred practices such as positive behaviour support, the use of appropriate alternative and augmentative communication strategies and autism friendly approaches (Beadle-Brown et al., under review). Sustaining active support and an overall person-centred approach to supporting people with severe and profound intellectual disabilities in group homes however has proved difficult (Mansell & Beadle-Brown, 2012). This suggests the importance of the current policy that active support should be central to the way staff in supported accommodation services work, and the value of longitudinal Australian research to understand the organizational structures and processes that sustain good active support. The consistent practice over time by all members of the staff team in respect of all residents, inherent in our rating scale was

evident in the strong team work and shared supervision in the two better performing homes and are important elements of culture in better performing group homes (Bigby et al., in press).

### **Limitations**

Although the two groups of services were not completely comparable in terms of client characteristics, the difference was in the right direction. The services providing poorer outcomes for people were those providing for more able if somewhat older residents. This implies that the better outcomes achieved by the voluntary sector services were not an artefact of level of ability and much more likely to be due to staff practices. Generally research has found that these are the two factors that most reliably predict quality of life of people with intellectual disabilities (as reviewed in Mansell and Beadle-Brown, 2012).

Secondly the method for coding the qualitative data was developed specifically for this study. Inter-rater reliability was not assessed but the final ratings were made by two people, moderated and then a sample of ratings checked by a third person familiar with the quality of life domains, person-centred approaches and working with people with severe and profound intellectual disability.

### **Conclusion**

The analysis in this paper suggests the potential weakness of judgements about the quality of services made by organisations, staff or others such as community visitors without systematic investigation or observations. Only when values and intentions are operationalized is it possible to put them into practice and in order to make judgements about the quality of services, it is necessary to be able to define what expected outcomes look like. Policy documents and the literature are replete with examples of poor staff practices in group homes, but there are few of good practice that relate specifically to people with more severe levels of impairment derived from systematic investigation across quality of life domains rather than

anecdote. This paper provides a framework, qualitative indicators and examples of good outcomes relevant to people with more severe levels of intellectual disability together with associated staff practices. These can be used by auditors, community visitors, funders, advocates or family members to guide observation and judgements about group homes. For example, a guide to visiting based on this work has been adopted by the Victorian Community Visitor program (Bigby & Bould, 2014).

The findings suggest the importance of intermittent observation of group homes at different times of the day and days of the week in order to capture both the nature and consistency of staff practices. Observation is a key adjunct to inspection of paperwork or interview with staff in judging the quality of a group home. Any observations must always be considered in the particular context in which they occur, and can give real insights into what is actually happening for residents in group homes, rather than what should happen or is intended to happen. Observations cannot be subject to the type of falsification that occurred in paper work in homes in Victoria (Victorian Ombudsman, 2011).

Hundreds of people with more severe and profound intellectual disabilities are likely to remain in groups homes in Australia in the coming years. If they are to experience the type of improved quality of life foreshadowed in the recent Australian Disability reforms, significantly more attention must be given to observing and improving the quality of staff practices and ensuring more of these are *good*. This of course is also an issue in many other countries where group homes are still the dominant model or where no system of personal budgets exist and where for financial reasons, group homes are the only feasible option currently available (for examples in countries of Eastern Europe where the process of deinstitutionalisation is still in its infancy).

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Table 1

*Quality of Life Domains, Indicators of Outcomes and Associated Staff Practices Relevant for People with Severe or Profound Intellectual Disability*

Quality of Life Domain	Indicators
<p><b>Emotional well-being</b></p> <p>Demeanour at ease</p> <p>Absence of challenging and self-stimulatory behaviour</p>	<ul style="list-style-type: none"> <li>● People <b>appear content</b> with their environment, their activities and their support, they smile and/or take part relatively willingly in a range of activities (including interactions) when given the right support to do so</li> <li>● People appear <b>at ease with staff presence and support</b></li> <li>● People appear <b>comfortable in their environment</b> including with the level of arousal.</li> <li>● People appear pleased when they <b>succeed in activities, do something new or experience interaction</b> with new people in their environment</li> <li>● People <b>do not show challenging behaviour</b> or spend long periods in self-stimulatory behaviour</li> </ul>
<p><b>Interpersonal relations</b></p> <p>Positive family relationships</p> <p>Positively regarded by staff</p> <p>Breadth of social relationships</p>	<ul style="list-style-type: none"> <li>● Staff <b>are proactive and people are supported to have positive contact</b> with their family on a regular basis. Family can visit whenever they want to.</li> <li>● <b>People experience positive and respectful interactions</b> with staff and others in their social network including co residents</li> <li>● <b>People are positively regarded</b> by staff, they are seen as essentially human ‘like us’ and differences related to impairment or health are attended to from a value neutral perspective.</li> <li>● People have <b>members in their social network other than paid staff and immediate family</b> – and are supported to meet new people with similar interests both with and without disabilities, and to make and maintain friendships with people outside of their home as well as those within their home</li> <li>● From most of these contacts, <b>people experience affection and warmth.</b></li> </ul>
<p><b>Material wellbeing</b></p>	<ul style="list-style-type: none"> <li>● People have a home to live in that is <b>adapted to their needs</b> in terms of location, design, size and décor within the constraints of what is culturally and economically appropriate</li> <li>● People have <b>their own possessions</b> which can be seen around their home.</li> <li>● People have enough money to <b>afford the essentials and at least some non-essentials</b> (e.g. holiday, participation in preferred activities in</li> </ul>

	<p>the community)</p> <ul style="list-style-type: none"> <li>• People are supported to manage their financial situation so they <b>can access their funds</b>, use them in accordance with their preferences, (preferences are sought and included in decisions about holidays, furniture or the household budget)</li> <li>• People have access to some form of <b>transport in order to access the community</b></li> </ul>
<p><b>Personal development</b></p> <p>Engaged</p> <p>Participation in meaningful activities and interactions</p>	<ul style="list-style-type: none"> <li>• People <b>are supported to engage</b> in a range of meaningful activities and social interactions that span a range of areas of life (meaning full occupation or employment, household, gardening, leisure, education, social)</li> <li>• People <b>are supported to try new things</b>, have new experiences with just enough help and support to experience success and thus to develop their skills.</li> <li>• People are supported to demonstrate what they can do (their competence) and <b>experience self-esteem</b>.</li> </ul>
<p><b>Physical wellbeing</b></p> <p>General health</p> <p>Access to acute and preventative health care</p> <p>Healthy lifestyle</p>	<ul style="list-style-type: none"> <li>• People are supported <b>to be safe</b> and well in their own home and in the community (without staff being risk averse)</li> <li>• <b>Personalised and respectful support with personal care is provided well and promptly</b> –all aspects of personal care reflect individual preferences as well as specific needs in respect of things such as swallowing and provided <b>The environment is safe and healthy</b> (e.g. environment not too warm or cold, no uneven or dangerous floors), people can move around their environment safely,</li> <li>• People are <b>supported to live healthy lifestyles</b> at least most of the time – good diet, some exercise etc.</li> <li>• <b>Pain or illness</b> are recognised and responded to quickly</li> <li>• People are supported to <b>access healthcare promptly</b> when ill and preventative care such as regular health checks appropriate to age and severity of disability – are not over or under weight – specific health issues are managed.</li> </ul>
<p><b>Self-determination</b></p> <p>Day to day decision making</p> <p>Autonomy</p> <p>Support with decision making</p> <p>Personalisation</p>	<ul style="list-style-type: none"> <li>• People <b>are offered and supported to express preferences and make choices</b> about day to day aspects of their lives which means people’s own agendas and preferences guide what staff do rather those of staff</li> <li>• Staff use <b>appropriate communication to support choice and respect people’s decisions</b></li> <li>• People are <b>supported to understand and predict</b> what their day will be like, based on their own preferences and agendas</li> <li>• People are supported to be <b>part of person-centred planning and other decision making processes</b> as much as possible and to have someone who knows them well and who can help others to understand their desires and wishes, such as an advocate or members of circle of support</li> <li>• People lead <b>individualized lives</b> rather than being regarded as part of a group of residents</li> </ul>

<p><b>Social Inclusion</b></p> <p>Community presence</p> <p>Community participation</p>	<ul style="list-style-type: none"> <li>• People <b>live in an ordinary house in an ordinary street</b> in which other people without disabilities live</li> <li>• People are supported to have a <b>presence in the local community</b> – access community facilities (shops, swimming pool, pub, café) and <b>are recognised, acknowledged or known</b> by their name to some community members</li> <li>• People are supported to <b>take part in</b> activities in the community not just with other people with disabilities. They actually <b>do part of</b> the shopping, for example.</li> <li>• People are supported to have a <b>valued role, to be known or accepted in the community</b> – membership of clubs, taking collection in church, are viewed respectfully by people in the community (e.g. shopkeeper/bus driver/neighbours makes eye contact with them and call them by name), people are helped to be well presented in public, staff speak about people respectfully and introduce people by their name</li> </ul>
<p><b>Rights</b></p>	<ul style="list-style-type: none"> <li>• <b>People are treated with dignity and respect in all their interactions and have privacy.</b></li> <li>• People have <b>access to all communal areas</b> in their own home and garden, and are supported to come and go from their home as and when they appear to want to.</li> <li>• People have <b>someone external to the service system</b> who can advocate for their interests</li> <li>• People can physically access transport and community facilities that they would like to or need to access.</li> <li>• People are <b>supported to take part in activities of civic responsibility</b> – e.g. voting, representing people with disabilities on forums, telling their story as part of lobbying for change etc.</li> <li>• People and staff are <b>aware of and respect the arrangements in place for substitute decision making</b> about finances or other life area (guardianship, administration)</li> </ul>

Table 2

*Overview of the Residents and Settings*

	<i>Ordinary Life</i> houses				<i>Making Life Good</i> houses		
	Hesta Ave	Tiger St	Bee Lane	Apollo Drive	Market Street	Oakland Ave	Ashwood Grove
Sector	Non-government	Non-government	Non-government	Government	Government	Government	Government
Type of house	Purpose-built	Purpose-built	Adapted ordinary house	Purpose-built	Purpose-built	Purpose-built	Purpose-built
Approximate number of years that the house had been open at the start of the project	11	11	20	5	< .5	< .5	< .5
Night staffing	Active night	Active night	Sleep-over	Sleep-over	Sleep-over	Sleep-over	Active night
No. of residents	6	6	5	4	5	6	5
Men/women	2/4	3/3	1/4	0/4	5/0	3/3	5/0
Mean age (range)	36.0 (30 – 46)	43.4 (39 – 48)	30.2 (21 – 39)	60.3 (56 – 65)	52.0 (48 – 57)	51.7 (42 – 64)	52.8 (35 – 70)
Mean estimated Part 1 ABS score (range)	80.6 (43.2- 165.9)	67.2 (47.9 - 99.9)	68.2 (26.7 - 123.5)	145.3 (132.9 - 165.9)			
Level of impairment (IQ) <sup>a</sup> (No. of residents)	Moderate					4	
	Severe				4	2	4
	Profound				1		1
Percentage socially impaired	50.0%	50.0%	60%	25%			
Percentage with a physical impairment	83.3%	83.3%	100%	0%			
Percentage non-verbal	66.7%	100%	40%	50%			

<sup>a</sup>Based on measurement of IQ, taken from the residents' personal files

Table 3

*Rating of Group Homes in 'Ordinary Life' and 'Making Life Good' Studies on Quality of Life Outcome Indicators*

	Max	<i>Ordinary life homes</i>				<i>Making life good homes</i>		
		Hestia Ave	Tiger St	Bee Lane	Apollo Drive	Market St	Oakland Ave	Ashwood Grove
<b>Total score</b>	24	<b>22</b>	<b>22</b>	<b>18</b>	<b>14</b>	<b>8</b>	<b>7</b>	<b>6</b>
Emotional wellbeing	3	3	3	3	1	1	1	0
Interpersonal relations	3	2	2	2	1	1	1	1
Material wellbeing	3	3	3	2	3	1	2	2
Personal development	3	2	2	2	2	1	1	1
Physical wellbeing	3	3	3	3	3	2	1	2
Self-determination	3	3	3	2	1	1	1	0
Social inclusion	3	3	3	1	1	0	0	0
Rights	3	3	3	3	2	0	0	0