Identifying Good Groups Homes for People with Severe Intellectual Disability: Qualitative Indicators using a Quality of Life Framework

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Continuing Importance of Group Homes

- Approx. 17,000 people live in group homes - most have intellectual disability
- Will remain dominant form of supported accommodation in short to medium term
- Reform emphases choice - type of support and provider
- Making judgements about quality of services will become more important for consumers
- And hopefully for the NDIA to inform decisions about what can be purchased
- Expected outcomes often at high level of abstraction and not tailored to people with more serve intellectual disability
- 'inadvertent trick where least impaired people are used in the imagery to stand in for all others' (Burton & Kagan, 2006)'
- All examples of good homes were for people with mild intellectual disability

Aims

- **Address the difficulties**
  - Staff to translate abstract concepts such as participation, inclusion, choice into expected outcomes to guide practice
  - For families or community visitors to know what to observe in order to make judgments about quality
- **Acknowledge that quality of services and outcomes for this group are closely tied to staff practice**
  - Expect to see a person supported to ….be engaged ..make choices
- **Specifically twofold**
  - Differentiate between good and underperforming homes – to describe culture in good homes – way of comparing 7 homes
  - Develop set of qualitative indicators that translate abstract concepts and expectations into concrete examples of expected good quality of life outcomes and associated staff practices for people with severe and profound intellectual disability

Method

Overview

- **Used qualitative data collected using participant observation from two studies**
  - Making life good in the community - 3 houses, 16 residents, average 12 visits average 6 hours - [determined to be underperforming]
  - Ordinary Life – 4 houses, 21 residents – 22 visits average 3 hours [claimed to be 'best of their kind']
  - Most residents severe to profound intellectual disability and other complex physical, health or communication needs
  - Used quality of life domains (Schalock et al, 2002) as framework to code and extract data – recast domains to reflect life activities significant for this group and support required to achieve outcomes

Quality of Life Domain	Indicators
Emotional well-being Demeanour at ease Absence of challenging and self-stimulatory behaviour	• People **appear content** 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 • People appear **at ease with staff presence and support** • People appear **comfortable in their environment** including with the level of arousal. • People appear pleased when they **succeed in activities, do something new or experience interaction** with new people in their environment • People **do not show challenging behaviour** or spend long periods in self-stimulatory behaviour
Interpersonal relations Positive family relationships Positively regarded by staff Breadth of social relationships	• Staff **are proactive and people are supported to have positive contact** with their family on a regular basis. Family can visit whenever they want to. • **People experience positive and respectful interactions** with staff and others in their social network including co residents • **People are positively regarded** 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. • People have **members in their social network other than paid staff and immediate family** – 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 • From most of these contacts, **people experience affection and warmth**.
Material wellbeing	• People have a home to live in that is **adapted to their needs** in terms of location, design, size and décor within the constraints of what is culturally and economically appropriate • People have **their own possessions** which can be seen around their home. • People have enough money to **afford the essentials and at least some non-essentials** (e.g. holiday, participation in preferred activities in the community) • People are supported to manage their financial situation so they **can access their funds**, use them in accordance with their preferences, (preferences are sought and included in decisions about holidays, furniture or the household budget) • People have access to some form of **transport in order to access the community**

Personal development Engaged Participation in meaningful activities and interactions	• People **are supported to engage** 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) • People **are supported to try new things**, have new experiences with just enough help and support to experience success and thus to develop their skills. • People are supported to demonstrate what they can do (their competence) and **experience self-esteem**.
Physical wellbeing General health Access to acute and preventative health care Healthy lifestyle	• People are supported **to be safe** and well in their own home and in the community (without staff being risk averse) • **Personalised and respectful support with personal care is provided well and promptly** –all aspects of personal care reflect individual preferences as well as specific needs in respect of things such as swallowing and provided **The environment is safe and healthy** (e.g. environment not too warm or cold, no uneven or dangerous floors), people can move around their environment safely, • People are **supported to live healthy lifestyles** at least most of the time – good diet, some exercise etc. • **Pain or illness** are recognised and responded to quickly • People are supported to **access healthcare promptly** 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.
Self-determination Day to day decision making Autonomy Support with decision making Personalisation	• People **are offered and supported to express preferences and make choices** about day to day aspects of their lives which means people's own agendas and preferences guide what staff do rather those of staff • Staff use **appropriate communication to support choice and respect people's decisions** • People are **supported to understand and predict** what their day will be like, based on their own preferences and agendas • People are supported to be **part of person-centred planning and other decision making processes** 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 • People lead **individualized lives** rather than being regarded as part of a group of residents

Social Inclusion Community presence Community participation	• People **live in an ordinary house in an ordinary street** in which other people without disabilities live • People are supported to have a **presence in the local community** – access community facilities (shops, swimming pool, pub, café) and **are recognised, acknowledged or known** by their name to some community members • People are supported to **take part in** activities in the community not just with other people with disabilities. They actually **do part of** the shopping, for example. • People are supported to have a **valued role, to be known or accepted in the community** – 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
Rights	• **People are treated with dignity and respect in all their interactions and have privacy.** • People have **access to all communal areas** in their own home and garden, and are supported to come and go from their home as and when they appear to want to. • People have **someone external to the service system** who can advocate for their interests • People can physically access transport and community facilities that they would like to or need to access. • People are **supported to take part in activities of civic responsibility** – e.g. voting, representing people with disabilities on forums, telling their story as part of lobbying for change etc. • People and staff are **aware of and respect the arrangements in place for substitute decision making** about finances or other life area (guardianship, administration)

Method continued

- Rated each house on each domain using 4 point scale to reflect the proportion of people in the home who were achieving each quality of life domain and how consistent this was.
  - **0** = outcome was not present for any residents
  - **1** = mixed outcome, partial or strong outcomes for some residents some of the time, [only some indicators present some of the time for some people]
  - **2** = partially good outcome for all residents most of the time [most indicators mostly present for most people]
  - **3** = strong outcome for all residents most of the time. [all present for everyone all the time]
- Use of qualitative data – collected at different times over a long period when different staff were on duty, avoids draw backs of snap shot observations at one point in time

Findings - Could the homes be differentiated? Yes

Were the houses claimed as good actually good?

No 4 homes claimed as good were better than underperforming but could have been better

- Three highest scoring scored relatively poorly on interpersonal relationships and personal development

	Max	*Ordinary life homes*				*Making life good homes*		
		Hestia Ave	Tiger St	Bee Lane	Apollo Drive	Market St	Oakland Ave	Ashwood Grove
Total score	24	**22**	**22**	**18**	**14**	**8**	**7**	**6**
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

Qualitative Indicators - Examples - Emotional Wellbeing

Emotional well-being Demeanour at ease Absence of challenging and self-stimulatory behaviour	• People **appear content** 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 • People appear **at ease with staff presence and support** • People appear **comfortable in their environment** including with the level of arousal. • People appear pleased when they **succeed in activities, do something new or experience interaction** with new people in their environment • People **do not show challenging behaviour** or spend long periods in self-stimulatory behaviour

3 better houses all strong on this dimension:

- Judgement of well-being – satisfaction - based on interpretations of frequency and tone of residents' behaviour, body language, facial expressions, and vocalisations – and social interactions between residents and staff or family, many involved social touch or joshing, or enjoyment of activities initiated by staff

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. …….She takes his hands and he touches his lips to her cheek. 'I'm glad you're so happy' she says. (Tiger St)

Qualitative Indicators - Examples - Interpersonal Relations

Interpersonal relations Positive family relationships Positively regarded by staff Breadth of social relationships	• Staff **are proactive and people are supported to have positive contact** with their family on a regular basis. Family can visit whenever they want to. • **People experience positive and respectful interactions** with staff and others in their social network including co residents • **People are positively regarded** 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. • People have **members in their social network other than paid staff and immediate family** – 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 • From most of these contacts, **people experience affection and warmth**.

None of the house strong – most residents no more than passing acquaintance with people other than staff or family –one exception

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).

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)

Staff played significant part in people's life –quality of their interaction important – upbeat – fun

"We try and bring a sense of joy into the house, music, happiness"

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).

Qualitative Indicators - Examples – Personal Development

Personal development Engaged Participation in meaningful activities and interactions	• People **are supported to engage** 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) • People **are supported to try new things**, have new experiences with just enough help and support to experience success and thus to develop their skills. • People are supported to demonstrate what they can do (their competence) and **experience self-esteem**.

Right amount of support to be engaged – expand opportunities so can experience choice – in home, in community, in planning for activities - use of Active Support
Not consistent in better houses

> 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)
>
> 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)

Setting people up

> 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 9th. (Bee Lane)

Engagement in social interaction very positive but whilst staff did domestic activities meant lost opportunities

Conclusions

- Houses identified as good – not that good
- None of the better houses performed strongly on domains of personal development or interpersonal relations – [our research suggests this is common]
- Much greater potential for engagement – policy re active support?
- Rapport and social interaction high but most communication verbal and above comprehension, reliance on context rather than alternative forms to communication
- Distinctive culture in better houses – and leadership processes – shared monitoring, strong team work and leadership [see Bigby et al 2014)
- Demonstrate weakness of judgment without systematic investigation
- Framework of qualitative indicators outcomes and practices – can be used for staff training but also by auditors, community visitors, funders, advocates or family to guide observation
- Guide to Good Group Homes and Guide to Visiting for Vic OPA and CV program
- What to look for and what to ask staff

Office of the Public Advocate

Guide to Visiting and Good Group Homes

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Key references and resources

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