



LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE



Family perspectives about group home experiences of people with severe intellectual disabilities

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Background and Aim

- Increased emphasis hearing from service users
- Seldom hear people with severe or profound intellectual disabilities
- They are also underrepresented by advocacy groups
- Family members with close relationships likely to have insights into quality of services
- The limited research on family perspectives about quality accommodation services suggests families want:
 - **Acknowledged as partners - value good relationships with staff** (McKenzie, et al., 2018; Jensen et al., 2018; Koelewijn et al. 2021; Bright et al., 2018).
 - **Continuity of support - staff to know their relative** (Shipton & Lashewitz, 2016; Koelewijna et al., 2021).
 - **Relative treated respectfully - supported to be engaged and exercise self-determination** (Koelewijn et al., 2021; Mckenzie et. al., 2018)

Aim and method

- What involved family members think about the quality of the group home where their relative lives and what is important to quality.
- Part of a longitudinal study of group homes using observational methods
- Recruited 23 family members of 21 people with severe intellectual disabilities
- In weekly contact (2 brothers, 2 fathers, 11 mothers, 8 sisters (for 2 people 2 family members))
- From 17 group homes managed by 4 organisations
- Semi structured interviews - perceptions of service quality
- Recorded and transcribed
- Qualitative analysis using grounded theory methods

People whose family members participated

- Average age 52 years (28 – 80)
- Adaptive behaviour scores average 90 (27- 151)

Objective quality of services

- Active Support average 52%. (23%-91%) (66% is good Active Support)
- Frontline Practice Leadership average 2.75/5 (2- 3.6)

'Life's pretty good at the moment'

- Most were 'happy' with the quality of service - at the current time
- Staff, leadership & teamwork

Look, I think I'm very lucky with the staff that we've got. They seem to work together harmoniously, and I never see any backbiting or what have you with them. There doesn't seem to be any politics, really, amongst them...If the present staff stay on, I would be more than happy for him to stay where he is actually....the set-up he's got there, the care ...Yes, I'm very happy with it. (Kris)

- No one would support a move
- Sense of uncertainty and dread about change

We know that these good people won't be around forever...we do dread that day all the time. There's **always that fear in the back of our mind** that what is working well now may not continue to work well in the future. And what is a good story for her now may end up as a bad story in the future. (Alice)

Frequent changes

- Leadership - variable strengths

...they stay for three months, maybe six months, maybe a year, then they leave... there've been some really, really good ones, and there's been some real shockers, and at the moment, we don't have one at all' (Peter)

We didn't have a team leader for six months. **it was an absolute mess**" (Kerry).

- Atmosphere – changed by new leaders

...it was just a wonderful home all the clients and the staff were in this happy working environment....he took leave and a temporary house supervisor came. **She undermined protocols that were working really well.**

She changed the dynamics of the house (Alice)

- Support workers – don't know the people they support

...but they just move on...so there's nobody there now who's been there a long time (Kerry)

And when agency staff come in, **they don't know one client from another**...it's all guesswork for them and it can be a bit of a risk... **they get too up close -in her personal space...she's going to lash out.** (Alice)

Importance of strong leadership

“only works when you've got a person giving good clear leadership”

- Someone knows what's going on
- Monitoring for when things go wrong
- Ensuring staff teamwork and mentoring
- Problem solving
- Exploring new options and pushing boundaries for residents
- Communicating with families

there's staff that comes and goes...you need a manager who needs to say, 'That fridge needs to be cleaned out and that needs to be looked after.' ...they need **one person in there who knows what's happening**...somebody that is **actually controlling what's being made on the menu**...how do we know that Julie isn't eating spaghetti bolognese every night of the week because there's a different carer that comes in and that's their go-to meal? “Oh, well, we'll have - I'll make a spag bol,” and then the next one comes in, “Oh, I'll make a spag bol.” You don't have that **overall managed situation**. I think that's where it lacks. (Meagan)

Good leaders - more than good managers

- Caring – compassionate - good communicators
- Have energy and passion
- Know and have good relationship with the people they support
- Ensure a collective approach to support

I love her energy and her passion for people with a disability. I mean, she really loves them, and she's close to them. They relate to her. She talks to them. ..you can have a person who's got all the administrative skills in the world, and that can run the house efficiently, but if they don't have the compassion and the pull, they'll never warm to her. (Belinda)

this way of working in the house that Roy 's set up. I know they have monthly, weekly meetings, and they'd, you know – say Archie was a bit off or something. **They'd discuss that, and they'd sort out what to do with it...**(Margaret)

Good support workers

- ‘Lovely’ ‘caring’ ‘understanding and kind’

- Strong relationships with people they support

I know that they care about him because I can see when I've been to the house and They seem to go out of their way to make sure he has what he needs. (Kerry)

- Do more than ‘they have to do’

There are two kinds of staff that get into disability care. The ones who really care and want to make a difference, and the ones who are there who couldn't get a job anywhere else, and it's only financial to them. And so, they're very much removed from the client and they're very cold. (Alice)

- Knew the people they supported

I think the thing is getting to know the client. Julie is non-verbal, so Julie can't say, “Well, I prefer to wear that top today, or I'll prefer to wear those trousers.” I think it's more of actually knowing the person that you are working with to understand what their likes and dislikes are. I don't think there's enough time spent by some of the carers to get to know the individuals. (Meagan)

Perceptions of the external environment

- Creating paperwork and transactions that undermine quality
- “More administrators now than ever before”

all they seem to be doing is doing reporting and stuff on their computers and stuff like that. They don't seem to interact with the clients (Helen)

They are very much bogged down in paperwork... **they're being overwhelmed with too much paperwork and less hands on.** ... what used to be like a one-page document...is now turning into 20 pages per agreement.. (Alice)

- Little contact with organisations that manage services and confusion with system

No, I haven't met anyone from there yet...Yeah. I wouldn't even know where they are... (Kerry)

I haven't really cared because my communications has always been with the house staff. (Alice)

If you can figure out who's who. There's so many - even doing the NDIS plan, there was about eight people involved. (Sally)

Conclusion

- Family members resigned to uncertainty and changing quality of support
- But not interested in supporting a move
- Findings align with
 - Limited literature about families of people living in group homes,. They value
 - continuity of support, staff knowing their relative their relative being supported to be engaged and exercise self-determination (Shipton & Lashewitz, 2016; Koelewijna et al., 2021; Mckenzie et. al., 2018)
 - Literature - importance of practice leadership to good support
 - Literature – that supporting engagement, consistency and knowing the person are key to good support
- Service level more significant than the wider organisation
- Identified growth of paperwork and negative impact of NDIS on client focus
- Similar to recent research on practice leadership (Bigby et al., 2023)
- Suggests challenges of exploring alternative options for people with severe disabilities
- Major issues how to reduce staff change and strengthen leadership