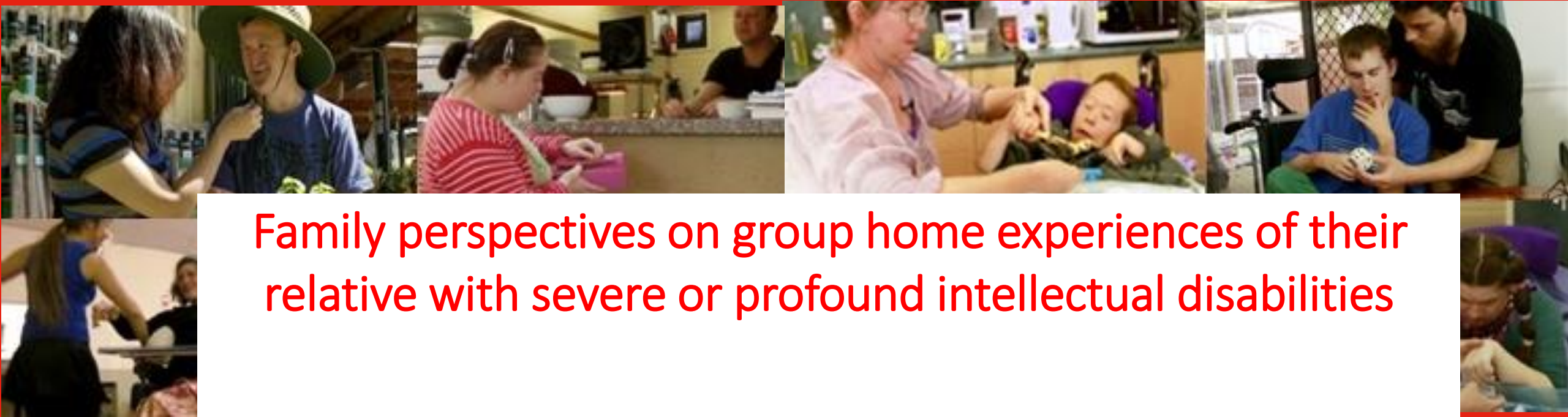




LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE



Family perspectives on group home experiences of their relative with severe or profound intellectual disabilities

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Background

- Growing emphasis on hearing what service users value and what needs to change
- Seldom hear directly from people with more severe or profound intellectual disabilities – also underrepresented by advocacy groups
- Reliance on observational studies to assess the quality of support in group homes
- Family members with close relationships to people in group homes likely to have insights into quality of support for their family member with severe or profound intellectual disability
- Very little research on family perspectives of quality. It suggests
 - Families want to be acknowledged as partners and value good relationships with staff or managers (McKenzie, et al., 2018; Jensen et al., 2018; Koelewijn et al. 2021; Bright et al., 2018).
 - Value continuity of support and staff knowing and understanding their family member (Shipton & Lashewitz, 2016; Koelewijna et al., 2021).
 - Want person to be treated with dignity and respect – supported to be engaged and exercise self determination (Koelewijn et al., 2021; Mckenzie et. al., 2018)

Aims

- Explore perspectives of family members of people with severe and profound intellectual disabilities about what is important to quality support in group homes.
- Identify how family perspectives line up with 'evidence' about what makes most difference
- Research questions
 - What do involved family members think about the quality of the group home where their family member lives?
 - If there were the opportunity would they want their family member to move?
 - What do they think is important to quality?

Method

- Part of a larger study of group homes using observational methods to measure the quality of Active Support and Practice Leadership
- Recruited family members who had consented on behalf of their relative with severe intellectual disability to participate in the observational study
- 23 family members of 21 people
- 2 brothers, 2 fathers, 11 mothers, 8 sisters (for 2 people 2 family members participated)
- All family members saw their relative or had contact at least weekly
- Semi structured interviews about perceptions of the quality of service, recorded and transcribed
- Qualitative analysis using grounded theory methods

People with intellectual disabilities whose family members participated

- Average age 52 years (28 – 80)
- Adaptive behaviour scores average 90 (27- 151)
- Living in 17 services managed by 4 organisations
- Active Support average 52%. (23%-91%) higher than 2022 average 42% for people with high support needs
- Frontline Practice Leadership average 2.75 (2- 3.6) similar to 2022 average

'Life's pretty good **at the moment**'

- Most were 'happy' with the quality of service or felt 'lucky' with it - at the current time
- No one would support a move elsewhere
- Combination of service level and individual factors – happy atmosphere, good supervisor and staff, family member getting on with other residents, comfortable with routines, having friends, and good external programs

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)

Uncertain quality - resulting from frequent changes

In leadership

“...at the moment, there is a temporary person in charge there... I have a great relationship with her... I don't know how long she's going to be there...**they stay for three months, maybe six months, maybe a year, then they leave...if there was some stability in that regard, you as a parent would go away feeling far more confident** (Peter)

Atmosphere of the service

...it was just a wonderful home that he had created where all the clients and the staff were in this just happy working environment....But one day he took a holiday leave for a couple of week and the area supervisor sent in a temporary house supervisor to cover. **She undermined protocols that were working really well. She changed the dynamics of the house...she interfered** [and]didn't respect what was working so well in the house. (Alice)

In support workers

...but they just move on themselves and they get moved around so there's nobody there now who's been there a long time but the house manager now... **Maybe they could have the staff stay longer...that's what I'd like to see...**Well, I suppose if you knew that somebody was there, you knew who was there ...you could rely on them and feel comfortable that the care would continue instead of different faces every day. (Kerry)

Change impacts on quality of support and wellbeing

Workers don't know the person – trigger negative responses

And when agency staff come in, they don't know one staff client from another. And so it's all guesswork for them and it can be a bit of a risk...they try so hard with Tammy, they want to be her best friend, but the trouble is **if they get too up close and personal -in her personal space...she's going to lash out.** (Alice)

Person doesn't know support workers – feels unsafe

You worry about all of that all the time. Sometimes, she rings me when there's new carers there that she doesn't know, and she goes, "Dad, **I don't feel safe, can you come over?**" And I go over (Peter)

Inconsistent or no leadership

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 in the house. You can imagine, **it was an absolute mess**" (Kerry).

Change brings

Sense of uncertainty

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)

Resignation

Yeah. It's a bit hard with the amount of casuals that come in. But you know that it's like a hospital and positions have to be filled and people move on. And then you might have somebody away on holidays and things like that. But look, **we've gotten used to it over the years.** (Glenise)

What's important ? Strong leadership

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

Brings predictability and continuity to a changing environment

Someone knows what's going on - monitoring for when things go wrong, ensuring teamwork – leading and mentoring staff, problem solving, exploring new options and pushing boundaries for residents

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.' ...if there's something broken it just doesn't go from one person to the other, they need **one person in there who knows what's happening**...you need 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)

Ensuring regular communication with families

She's great. She keeps me informed with everything. (Damien)

Qualities of good leaders - more than good managers

- Caring – compassionate - good communicators
- Have energy and passion
- Know and have good relationship with the people they 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. And she's just a divine girl. We love her. (Belinda)

Good leaders ensure a collective approach to support

..these guys have just taken to 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...** He just talked to his staff and said, “Look, you know, Archie's got into this pattern. So, if he starts waking, getting up at night, we can't tell him not to do that, you know, that will continue for a while. For heaven's sake, give him a cup of tea, you know, what's the matter if he has a cup of tea or not?” They used to say, “No, you've got to go back to bed and wait till six o'clock, you know, crap like that.” And so, those rules, stupid rules were enforced...you know, they just blocked him. And then, again, you get a reaction. (Margaret)

Weak leadership can mean

Poor staff moral and poor outcomes for residents

Yeah, untidy, things to be done, nothing organised in terms of outing or activities for the guys there – There's **no sense of happiness in the place**. Everyone does their job, as I said, they cook their meals, and I'm not disputing that for a moment, and that's all, that sort of things. But **just a general down spiral in terms of the morale of the place....** in the sense of there's no spontaneity, no natural happiness – (Peter)

Distancing family

He could be quite dismissive in his manner. So, you sort of step back and think I really should ring him about that but then you don't like to because it's like sometimes **you just don't want to have a negative conversation**. It's like you're almost like oh I don't think I could handle that today so I won't ring him kind of thing. (Michelle)

Good support workers

‘Lovely’ ‘caring’ ‘understanding and kind’

Have strong relationships with residents

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)

Know the people they support

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)

Poor support workers can mean

Disengagement

'Looking after her, maybe yes, but not engaging with her no' ...When Lolya's hanging around with her wheelchair, and they've got nothing to do, and they're sitting down on their phones or watching TV, call her over, or go over and talk to her – engage in conversation, because that's what Lolya likes. As I said, she can't entertain herself. But very rarely do they do that. (Peter)

Staff centred approach rather than person centred

they just sort of leave him to do his own thing....but it seems to turn into a social event, not a formal workplace. Like they've got the telly on and they're chatting amongst themselves...it becomes a little bit more about them than about Richard (Michelle)

Simplistic interpretations of rights

He is 80kgs and he's just put on about 12- 13kgs in the last year or two, and I've complained and complained and complained, and the response is, "We can't stop him from eating something. He's got free choice....And we can't prevent them. We can't lock cupboards," (Helen)

External influences

Quality undermined by more paperwork

“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 particularly. (Helen)

They are very much bogged down in paperwork...If it gets worse, then I have no doubt that more and more good people will leave disability care because **they're being overwhelmed with too much paperwork and less hands on.** ...as the house supervisors have said is, “We're here to look after the client, but more and more we're being removed from the client and having to manage the amount of paperwork for all these different entities”... 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 NDIS

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)

Conclusions

Most family members happy at that point in time – not interested in supporting a move

Resigned to uncertain and changing quality of support

Value good leadership - consistency, teamwork, communication

Value interested, caring and concerned staff who know their relative

Family views align with

- Limited literature about families and group homes
- Literature about importance of practice leadership to good support
- Literature that engagement, consistency and knowing the person are key elements of good support

Service level more significant to families 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 in exploring other housing options for people with severe and profound intellectual disabilities – families 'happy'

Raises the questions are change and uncertain quality of support unique to group homes?

Major issues are reducing staff changes and improving practice – better Active Support greater staff satisfaction – less change?