Guide to Visiting and Good Group Homes

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Acknowledgements

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Good Group Homes for people with more severe levels of intellectual disability

Group homes are a very significant part of the system of services that supports people with intellectual disability. Approximately half of all Australian disability expenditure is on accommodation and most of this is on group homes. There are over 900 group homes in Victoria, that generally support four to six residents with intellectual disability. The National Disability Insurance Scheme (NDIS) will enable a more diverse range of options but some form of group home is likely to remain the dominant model for some time.

The future profile of residents is likely to change to include more people with severe and profound intellectual disability, as people with milder levels of impairment, who do not need to pool support funds, take up other options, and their places are taken by those with higher support needs.

Research has consistently shown that it is this group of people, with more severe intellectual disability, who are at greatest risk of the worst quality of life outcomes in group homes; this is the reason they are the focus of this short guide to Good Group Homes.

Aim of group homes

Disability policy is firmly based on a rights perspective that recognises people with intellectual disability have the right to be fully included in society and to a quality of life comparable with the general population. The aim of group homes, is to “enrich the quality of life of residents” and the task of staff to promote “participation in household and community activities, relationships with other people, decision making skills, and dignity and respect” (Department of Human Services, 2012). The abstract level of policy documents and the many different interpretations of concepts such as participation, inclusion and rights mean it can be difficult to imagine what expected outcomes look like for people with severe and profound intellectual disabilities. This is not helped by the tendency to use imagery of the least-impaired people in documents and training materials.

Research in Victoria suggests too that some staff think people have to be ‘realistic’ about what is possible for those with severe intellectual disability. Staff often reject ideas that people with higher support needs can make choices, be involved in day-to-day domestic activities or participate in things such as community organisations.

The task of staff is to promote “participation in household and community activities, relationships with other people, decision-making skills, and dignity and respect”.

Research has shown that people with more severe intellectual disability are at greatest risk of the worst quality of life outcomes
Inconsistent quality of life outcomes

The quality of life outcomes for residents in group homes are much better than cluster type housing or traditional institutions. But not all group homes consistently deliver high quality support. Some residents have very low levels of engagement in meaningful activity and relationships, and outcomes can vary enormously both within and between services. Outcomes for residents in some group homes are so compromised by poor staff practices that they are similar to those found in better small institutions. A study for example, found the culture of some group homes in Victoria, regarded residents as ‘other’ ‘childlike’ ‘not quite human’ and valued them differently from other people. Routines and decisions were centred around staff needs rather than residents, and staff were focussed on doing things for residents rather than with them.

Outcomes for residents in some group homes are so compromised by poor staff practices that they are similar to those found in better small institutions

Looking after the house and simple presence in the community was prioritised rather than engaging residents in domestic tasks, or supporting them to be known, or to participate in activities the community. Nevertheless, the quality of life outcomes that are possible in good small group homes cannot be achieved in larger settings.

Supporting people to exercise rights

The quality of staff support is critical to the quality of life of people with severe and profound intellectual disability. People with more severe intellectual disability need support to exercise their rights. Choice or control for instance may occur by staff responding to a person’s facial or body movement. Interpersonal relationships may manifest in momentary fun interactions. For this group, the exercise of rights and quality of life outcomes are inextricably connected to staff practices and particularly nuanced, manifesting in different ways from those for people with mild intellectual disability.

People with severe and profound intellectual disability find it difficult to act independently. They are reliant on staff to facilitate and interpret their communication, identify their preferences, generate opportunities for new experiences and participation, and support them to successfully engage in meaningful activities and relationships.

People with more severe intellectual disability do not understand complex language and may comprehend little of what staff say other than the sense of warmth or otherwise conveyed by the tone of their voice. They will use single words, signs or gestures to communicate preferences.
Just asking this group of people how they are doing or what they would like to do cannot be the only strategy to gain insight into their preferences or experience of living a group homes.

Quality of staff support – the value of observation

Without a doubt, good staff support is linked to good outcomes for residents in group homes. The ‘moment of truth’ in terms of residents’ quality of life lies in staff practices: how staff communicate, interact and provide assistance to them.

Good staff support is linked to good outcomes for residents in group homes

Many things influence the practice of staff. It is often what happens behind-the-scenes, mainly in the form of paperwork, that is the focus of quality audits and that gets the most attention. These include:

- an organisation’s values, procedures and practices
- the commitment of senior managers
- the method of monitoring staff practice
- arrangements for practice leadership
- regularity and focus of supervision and team meetings
- job descriptions
- recruitment processes
- induction and processes for translating high-level values into expectations
- guidance for practice.

It has been suggested that the more coherent and focused on resident quality-of-life outcomes these organisational aspects are, the better staff practices will be.

The true test of the effectiveness of paperwork, quality management, and staff training is how front-line staff behave every moment of the day:

- what staff think and do
- what staff say
- how staff regard residents
- how staff interact with residents
- how staff support residents every moment they are on shift.

Well-thought-out procedures only lead to good outcomes if they are put into practice and the plans are only effective if they are implemented. Paperwork is not infallible; it can only guide practice if staff know about it and use it, and only useful if it reflects what actually happens - not future intent or what should have been. How many staff on a shift, for instance, know about and use the content of residents’ communication plans, behavioral support plans or person centered plans?
What good staff practice looks like

The primary focus of this guide is what a good group home for people with more severe levels of intellectual disability looks like, what you should expect to see and hear if residents are experiencing a good quality of life – rather than what should be happening behind-the-scenes to make sure this happens.

There is a lot of evidence about poor staff practices and bad resident outcomes. However, compared to healthcare for instance, in disability, there is relatively little evidence about what constitutes good staff practices. In principle, we know the importance of providing support and things such as: adjusting communication style; adapting the environment; interpreting the meaning of behaviour; offering choices; and knowing residents well. For example, research showed that one highly rated service had a practice framework that included elements such as: active listening; positive language; plan of the day; active support; and choice and control.

The focus of this guide is what a good group home for people with more severe levels of intellectual disability looks like

There is particularly strong evidence about a person-centred approach called ‘Active Support’, which originated in the UK and the work of Kushlick (1966) who identified disengagement as a major problem in poor quality services. Person Centred Active Support was developed much further by Jim Mansell and Julie Beadle-Brown. It is an evidence-based practice whereby ‘staff provide just the right amount of assistance to enable service users to successfully take part in meaningful activities and social relationships, irrespective of their degree of intellectual disability or physical impairments’. This approach means that a person might only take part in some parts of a task; they do not have to do it all or do it independently to be involved in some of it.

Staff who use Active Support see that every moment has potential for a person to be engaged; provide little amounts of assistance often; provide graded assistance that is just enough of the right kind to enable a person to succeed in doing all or part of a task; provide opportunities for residents to exercise choice and control over many aspects of their lives, including all those small everyday things that are so important to everyone.
Front-line staff practice based on Active Support leads to better quality of life outcomes for people with intellectual disability:

- Active Support gives prominence to staff providing support for residents to be engaged in meaningful activity and social relationships.
- It is based on evidence that engagement is the way that many aspects of quality of life are realised.
  - personal development is only possible if people participate in activities that broaden their experiences;
  - interpersonal relations and social inclusion depend on interacting with other people;
  - physical health depends on lifestyle and activity.
- Active Support is not something that is scheduled for set times or with particular residents; it is a way of working for staff that is applicable at all times with all residents.

**Using quality-of-life domains as a guide to what to look for and what to ask**

The following sections use a quality-of-life framework to set out indicators for each of the eight domains for the type of outcomes and associated staff practice that might be expected to be seen in a good home. They are particularly orientated to people with severe or profound intellectual disability. Each set of indicators is followed by some exemplar excerpts taken from research on good group homes in Victoria.

Finally, for each domain there are four or five prompts that may be useful in guiding observations or discussion with staff if you are making judgements about the quality of staff practice or resident outcomes in a home.

This is not intended to be a definite list that must be used but a guide or prompt to your observations and discussion with staff. Community Visitors must rely on their own experience and judgment to decide whether these are useful in a particular house and to identify other matters that must also be pursued.
Personal development

Engaged: participation in meaningful activities and interactions - doing ‘with’ residents, not ‘to’ or ‘for’ them.

- People are **supported to engage** in a range of meaningful activities and social interactions that span a range of areas of life (meaningful occupation or employment, household, leisure, education, social, gardening)
- 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

These examples are all drawn from our research in group homes. Remember that these examples relate to people with severe and profound disability who are unlikely to understand complex language or use words to communicate.

**Examples of good practice**

The researcher sat down at the table near Olga. After a while, she grabs my hand and wants to lead me somewhere. I go with her and say that I don’t know what she wants. Marta [staff], picks up on the cue and accompanies her to the laundry, where she opens a cupboard and returns with a round tin that has some more craft material in. Marta explains that she wants some cotton.

Adele [staff] 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.

Her parents were very elderly… they used to dress her very old-fashioned, and, most of the time she didn’t go out to buy clothes, they just brought them. They said she wasn’t interested, in shopping, or anything like that, she didn’t care about clothes, all she wanted to do was look at books and DVDs. Now she’s a shopaholic, looking at clothes, and things like that… one of her aunties who hadn’t seen her for a few years didn’t recognise her because her hair was done beautifully, and she’d got these trendy clothes on, they couldn’t believe the change in her.

Fawn doesn’t like crowds. Now, for many years, she was never taken to shopping centres, she was never taken to stage shows. We then started taking her to more low-key, high school concerts, or performances like local performances. She liked the musical but she didn’t like the crowd. Once she was then more comfortable in the crowds, we started taking it further and further, and now she will actually attend a live show, in the city, at the Arts Centre, or theatres in the city.
Remember that these examples relate to people with severe and profound disability who are unlikely to understand complex language or use words to communicate.

Jake and Effie [staff] 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. Effie tells me later that if she did not prompt him to move then Jake would most likely stay in the same spot.

Jetta [staff] is collecting ingredients from the pantry, talking to Tess about what they need. All the basic ingredients are in Tupperware containers. Tess is given the self-raising flour, which sits on her lap, and she uses the joy-stick on her electric wheelchair to move herself to the kitchen. “Help me,” she says to Jetta. “Can’t reach”. Jetta takes the self-raising flour and puts it on the kitchen workbench. “I help,” says Tess and takes the measuring cup. ..Jetta asks Tess whether she wants to use the mixer. Tess says “No” and signs “Do you want to help? I can pass it to you.” probes Jetta. “No.” Whilst Jetta uses the mixer, Tess mimics her.

There were also photographs of Brendan washing and drying dishes and making a smoothie.

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.”
Room for improvement: is more participation possible?

Residents are often regarded as helping staff, to do things such as prepare meals or purchase goods in a shop. This may mean staff do much more of the task than necessary and many opportunities for involvement are lost.

Think about the missed opportunities in these examples, and what they might look like if staff thought ‘every moment has potential’.

Examples of practice that could be improved

Romeo [staff] gets out some bowls from a cupboard and puts them on the work-surface. He calls Maud to come and get her breakfast. Romeo takes the plastic top off the container containing the Weetbix and Maud helps herself to the cereal. She than adds some cereal from the other containers. Romeo adds some milk, takes the bowl, and puts it in the microwave and presses the start button.

Rowan was assisted, using hand-over-hand support to chop some onions, and Joan [staff] started putting things into a saucepan and stirring. After a few minutes, she asked Rowan if he would like to stir but then he watched on as Joan washed the lettuce, and prepared the salad.

Mandy [staff] wheeled Katie out into the garden to pick some herbs for the evening meal. Mandy talked to Katie as she picked herbs from the pots, and then put the herbs onto the tray on Katie’s wheelchair.
What to look for

- Are staff supporting residents to be engaged in activities around the home and the garden?
- How do staff prepare for activities and how do they present them to residents? Does the presentation use appropriate communication (e.g. speech plus handling materials, gestures) to make it clear what they are being invited to do?
- Are staff doing things for people – or with them?
- Are most opportunities to involve clients taken, for example in simple parts of tasks using hand-over-hand assistance, verbal or physical prompts if necessary
- How many missed opportunities do you notice?
- What are residents doing for most of the time you are observing? Are they engaged in meaningful activities or social interaction or engaged in passive listening or watching or sitting?
- Is the TV on? Is anyone engaged in watching it?

What to ask staff

- How do you know what residents like and dislike?
- Have any new activities been introduced or tried recently?
- Have staff revisited any activities they think residents don’t like to give it another go?
- How do staff support residents to be engaged when they are out shopping or using community facilities?
- Who does what? The gardening, housework, laundry, cooking, shopping?
Self-determination

Day-to-day decision-making, autonomy, support with decision-making and 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 than 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 a family member, an advocate or members of circle of support.
- People lead **individualised lives** rather than being regarded as part of a group of people.

Examples of good practice

The staff member purposely phrased questions to Lee which elicited either a ‘yes’ or ‘no’ response so that she could make a decision. For example, during afternoon tea they showed Lee a choice of snack, and asked if this is what she would like to eat. She responded ‘no’, so she was offered something else, to which she responded ‘yes’.

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. If I haven’t really seen him respond, then I just tell him, “Oh, we’ll go for this one, what do you reckon?”, and if he doesn’t yell out or anything then I’ll just take that as he’s happy with that.

Grace [staff] comes and looks at her and asks Niki whether she would like a coffee. She looks at her face for a response…and then sits and supports her to drink it, pouring small amounts of coffee into her mouth over a ten-minute period. Some of the coffee runs out of her mouth and is caught by the clothing protector…“Do you want some more?” asks Grace. Niki tips her head back and opens her mouth.
The staff member says that Hank was listening to Harry Potter on an audio book, and “He went berserk. He was cracking it”. She explains that he was telling us that he had heard it before and didn’t want to listen to it again.

Even if you don’t get a response from someone who doesn’t use language, you still ask the question: “Is this what you want? Would you like this?”, and you’re just always looking for that little response that sort of gets you, sort of the answer.

I’ve always gone in, and said: “What do you want to wear today? Do you want to wear this, or do you want to wear that ?” At the moment, he’s got a total, thing where he won’t wear trackie-pants? I try and trick him, and I’ll say to him: “So, are you wearing trackies today? “No?”….He suddenly just wants to wear jeans all the time and he’s given that choice, to do that.

We find that Niki likes to sit at that table with us, and if we move her to any other place, she cracks it; she completely goes berserk. She wants to be there, or else that’s just what we conditioned her to do, I don’t know, but she seems to prefer to sit right at the table listening to all the conversation, and being part of whatever’s going on at the table, and, to be here, maybe it’s her comfort zone, I don’t know, any other part, of the house, no.

The guys will tell us when they’re ready to go to bed. That’s why I don’t actually have a rigid routine because people think routines can’t be deviated from, so they’re guidelines, you know. It’s usually around this time that Golda might look tired and may want to go to bed, but Golda will walk into her bedroom if that’s the case. If not, she’ll walk up and go into the telly 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.

Tom [staff] asked Caroline: “Do you want another drink? Caroline pointed to ‘yes’ on her communication tray, and then Tom asked “Coffee?”, and again Caroline pointed to ‘yes’.

Our conversations are very one-sided, but that’s okay, because I know he can hear me and he does sometimes respond to me. I’m still getting to know Hank. It’s been a year, I suppose, twice a week, for a year. It’s fine, when we’re driving or going somewhere I just talk aloud. Sometimes I don’t say anything if I think he doesn’t want me to talk; or we put the radio on if he wants music. It’s a bit of guesswork, I suppose. I’ll put talkback on if he wants to just listen to the people talking.
What to look for

- Are residents doing things that reflect their individual choices and preferences or are they all doing something similar?
- How do residents know what their day will look like?
- How do staff offer choices to residents? Do they use communication aids?
- Do staff respect the choices made by residents?

What to ask staff

- Do all the residents go to bed and get up about the same time or does each have their own individual routine?
- How do you offer choice to a resident about what to eat, when to eat, what activity to do?
- How often do residents all go out together?
- What restricts individual choice for residents and how do you weigh up decisions about respecting a residents’ choice?
Interpersonal relations

Positive family relations, positively regarded by staff and breadth of social networks

- **Staff are proactive and people are supported to have positive contact with their family** on a regular basis. Family can visit whenever they want.
- **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.
- From at least some, ideally most, of these contacts, **people experience affection and warmth**.
- **People have members in their social network other than paid staff and immediate family**. People 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.

Examples of good practice

Hank’s family visited about a week ago, but the staff don’t really have much involvement, but that’s something that I think Hank wants to work on and we’re going to make more of an effort to visit his family, because they’re a bit busy. They can’t get here as much as I know they want to, so I thought that we could drive down and see them.

Madge [staff] supports Beth to make some telephone calls. The first call she makes goes to an answer phone. She points to another name in the filofax and ends up talking to David (nephew) and his partner Mary.

Hank comes to the table. Madge [staff] asks him whether people can look at his iPad. Madge shows the photographs that were taken with it at his parents’ 40th anniversary. His immediate family had been there. Madge says that he had been smiling, until Heather and she turned up at the end of the day. They attributed this to him assuming that he was going to be taken home. They used the iPad to write a journal about the trip.

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.
So you try and give them time on their own, so that they can just have time with their family member…respect their privacy and really just give them space, maybe we’ll make it so that they can have the lounge room to themselves or they’ll go out the back, just so that they’ve got their own time together.

The staff member knocks on the door, goes in, nudges Edie and speaks to her. Edie is lying in her double-bed, a red-velour cover over the doona, and a white throw at the base of the bed. Edie opens her eyes and wants to hold Pearl’s hands. They hold hands and clap them together.

The bus that the staff member wants is parked in front of a second bus. He tries to move it without moving the blocking bus. He does not succeed, gets out, and says to Seth: “You were right. I need to move the other bus”. He talks to Seth about going on a different route.
What to look for

- How do staff talk about residents? As people who can think, feel, communicate, understand?
- How do staff interact with residents? Is it warm and respectful?
- How do staff talk about family members of residents? Do they seem to know them and the degree of involvement they have in their relatives' lives?
- How do staff communicate with residents? Do they use any aids or alternative means of communication other than speaking?
- Is there separate crockery for staff and visitors? Why?

What to ask staff

- How do they support residents to be involved with family members?
- When did a resident last see a family member and what did they do together?
- How do they communicate with residents?
- Do residents have any communication aids? If so, are they used by all staff?
Social inclusion

Community presence and 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*; they can access community facilities such as shops, the swimming pool, pub, café.
- 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 activity, for example. Support can be families, volunteers, the members of community groups which the person attends.
- People are supported to have a *valued role, to be known or accepted in the community* – helping neighbours, 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.

Examples of good practice

They have been catching up with his friend Paddy, who has been in hospital, been doing some social things (the pictures) and outings.

The staff member says that the footy season is just about to start. They have been to some pre-season practice games at the local club…and Jacob is a member of the supporters’ club there…and then we go up there sometimes, just to go and sit in the park and have fish and chips, and people know him, from the footy club, because it’s only a small place, and they’ll come up and chat to him, and things like that. So people know him around, and then somebody will say: “Saw your mate, down Chirnside the other day.”

A number of events have been written in the diary. Two people are going to the Yarra Glen races on Melbourne Cup day; someone else is going greyhound racing.
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. So that sort of stuff is pretty important, to be able to have that connection with other people, apart from Hank’s housemates and staff. You can see it, in the way Hank comes to life sometimes.

I’ve never seen Hank as happy as when he has been up to Raymond and Sandy’s. Raymond has had a stroke so he can’t get around as well as he used to and he can’t do his gardening and he can’t do his shopping, so Clint [staff] and Hank go up there and do those things for him and with him and, when he walks in the neighbourhood, they sometimes walk with him to make sure he’s safe because he walks with a limp. So, there’s friendship as well as neighbourhood stuff going on.

The staff member comments on some of the photos that show the Apollo Street party. He says that this is an annual event that involves the whole street, which different people take turns to organise. They did it one year.

Ivan goes to a hairdresser, and the hairdresser now knows Ivan, and so every time he goes in there they notice [and say]: “Hi, Ivan. How are you?”
What to look for

- Does the house stand out from others in the street as being a group home? What could be done about this?
- Is there evidence of residents’ activities in the community or in the neighbourhood: photos, invitations?
- Is there evidence that staff are familiar with the local area? Local newspaper, council guides, fliers with events?
- If a resident returns home, where have they been? What have they been doing and who with?
- If a resident is going out, where are they going? What are going to do, with whom and how was the decision made to do this?

What to ask staff

- Do people in the neighbourhood recognise the resident? Does anyone say ‘hello’ when they are in the local area?
- Does the resident have any friends or acquaintances in the neighbourhood who know him or her by name?
- Do any of the residents belong to clubs or societies?
- Do any of the residents take part in a regular activity in the community with people without disabilities?
Emotional wellbeing

Demeanor, absence of challenging and self-stimulatory behaviour

- People appear **content with their environment**, their activities and their support.
- People **smile and/or take part willingly** in a range of activities when given the right support to do so.
- People appear **at ease with staff presence** and support.
- People appear **comfortable in their environment** including 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.
- **People with religious beliefs are supported to follow them** such as by attending church, having religious icons in their homes?

Examples of good practice

The staff member 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 vocalises loudly.

Pete is vocalising and Eliza [staff] asks whether he is stressing about the taxi. She comes up to him and touches his chest and tells him exactly what will be happening: “You’ll have your tea when you get back, then you’ll have a spa”. They both laugh.

The staff member says that she talks to Golda a lot and tries to understand the different tones in her vocalisations, looks for eye contact, and can tell the difference between her smiles and frowns.

Golda loves this room, she loves sitting here and she loves watching telly. Golda loves her own space, especially later on in the afternoon, and she’ll come up here herself.

The other day, when Niki really went berserk, it was like she’s telling us to shut up, so we’ve got to listen to her.

The staff member comments that Jake is in a lovely mood. While they have been sitting at the kitchen table, he has smiled a number of times. Jake moves his hand towards her. “I’m glad you’re so happy,” she says.
What to look for

- What is the demeanour of residents? Do they seem content? Do you see people smiling, laughing?
- Do staff respond to cues from residents and interpret their needs?
- Do residents seem resentful or resistant to staff support?
- Are residents engaged in self-harming, pacing or repetitive behaviour?

What to ask staff

- How do staff know what a resident wants or if they are not happy?
- What cues do residents give you which indicate their needs?
- Are any residents resentful or resistant to staff support?
- Are there particular things that trigger challenging behaviour and how have they addressed these?
Physical wellbeing

General health, access to acute and preventive health care and 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.
- **Personal care is provided** on a flexible basis rather than being routinised.
- **The environment is safe and healthy**, for example, 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, for example, they have a good diet, get some exercise.
- Pain or illness are recognised and responded to quickly.

Examples of good practice

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.

There is a concern that Pete is not getting enough fluid. From his expressions it looks like he has been getting cramp. The house staff have noticed that his drink bottle with cordial in it is being returned full. The day staff have been asked to write down what he has had to drink.

I think they feel very safe. They’re safe because we have a good network of workers here, and they’re never left with strange people, or if there is somebody, a new person, there’s always somebody who’s been there, you know, for a few years with them, so they feel very safe.

Stephanie [staff] feels Hank’s legs to make sure that he is not getting too warm. He is wearing black sweat pants which ‘absorb the heat’. “You love the warmth,” she says. She notices that Hank needs adjusting in his chair and calls out Daisy to help her move him upwards.

Adele [staff] takes her time to give Seth his food. She 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.
What to look for

- Are residents eating healthy, fresh rather than processed, packaged or fast food?
- Are residents a healthy weight?
- Are the bathrooms clean while retaining a ‘homely’ rather than sterile feel?
- Are household appliances clean and well-maintained and in working order?

What to ask staff

- How do residents get exercise and how often?
- Have residents had regular health screening recommended for their age and are abnormal tests followed up?
Material wellbeing

Material necessities for everyday life, including: home; possessions; money; transport

- 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 (through employment or benefits) to afford the essentials and at least some non-essentials, for example, a holiday or 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 or the household budget.
- People have access to some form of transport in order to access the community.

Examples of good practice

Cain is 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, when Cain was in his twenties. There is a landscape picture above his bed of sailing boats. There is another shelf above the small chest-of-drawers, which has a model boat and fisherman on it. On the small chest-of-drawers is an aromatherapy burner and a wooden box containing seven essential oils. Next to the heater is a portrait of Cain as a young man, painted by his father.

The house supervisor says: “I have an expectation that nobody will leave the house unless they are dressed beautifully, groomed lovely, because that’s how you and I would leave the house…If people only have beautiful clothes in their wardrobe, they’ll only have beautiful clothes to wear.”

Seth is going on holiday to Darwin where he will meet up with his family. Clint [staff] is going to take Seth to the airport, and asked if he can pick him up on the Sunday evening at 5.15pm. Jane, his mother, has been told that the house will take him to, and pick him up from, the airport.

It’s the respect for the guys, like putting the right person’s clothes in the right person’s cupboard, where you feel some people don’t care that much? We, you know, as a house, know how much people spend on their own clothes, so we look after them quite well.

Jo goes to basketball on Thursdays with his friend Mandy who lives in a house in the next suburb. They take it in turns to pay for a taxi to share, and to bring a staff member from their house.
What to look for

- Do residents have easy access to private space as well as shared space?
- How is the house adapted to take account of resident’s needs?
- Are the benches at a suitable height, are there communication aids that are used, is there easy access to the garden?
- Do residents have their own possessions around the house?

What to ask staff

- How are decisions about household expenses made?
- How are the arrangements to manage each resident’s finances managed to ensure their preferences are taken into account?
- Are there outstanding issues with house or vehicle maintenance that are causing difficulties?
Rights

Promote and protect rights, dignity and respect

- 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.
- All aspects of a person's identity are respected, for example, cultural, spiritual and sexual orientation.
- People understand how a person communicates and are committed to communicating in the best way for each person in all situations, for example, to ascertain a person's preferences and convey information about options and choices.
- People are supported to take part in activities of civic responsibility, for example, being part of community education forums, involved in telling their story, taking a role in service advisory groups or participating in some aspects of meetings.
- People and staff are aware of and respect the arrangements in place for substitute decision-making about finances or other life areas (for example if guardianship or administration orders are in place).

Examples of good practice

Tess came into the office and they chatted about her birthday.

The staff member says: “I feel that sometimes the families actually override what the person wants…I challenge it sometimes, but it is difficult as the more senior management of the organisation value families and their involvement.”

The organisation has a number of policy documents related to residents’ rights…One of the questions in the human rights checklist is ‘Can I choose who looks at my file?’ In this field note extract, the support worker (Grace) extends this principle to Niki’s diary. I ask Grace whether she knows where Niki’s diary is, which records her daytime activities. 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.
I talked to Madge [staff] after the meeting. The iPad will replace the hand-written diary. Hank was paid $400 for his part in the video ‘Living in the Community’. He bought the iPad with the money. “Hank’s an actor, and is looking for another part”, she said. The family e-mail addresses have been put into the memory. He can be helped to have faster and more regular contact with his family.

When Jake’s had to go to hospital, I’ve been there, and I’ve said to the staff: “Oh, he’s about to have a seizure”, and they’ll say: “How do you know that?” I explained it’s just because I know them, and they said: “Well we would have missed that.” So it’s being able to speak on their behalf, and understand them, what they like and what they don’t like. If I’m making their life what they want it to be, as best as I can, from what I know of them.

George always comes to resident meetings, where staff support him to use his computer to control the collage of photos displayed through the data projector which visually represents what residents have done in the past month and shows pictures of potential new activities in coming weeks.
What to look for

- Do staff behave and talk in a way that suggests residents have rights and this is their home?
- Do staff knock on bedroom, bathroom and toilet doors before they enter?
- Who opens the front door?
- Do residents have access to the office and all other parts of their home?

What to ask staff

- Do residents have anyone who acts as their advocate?
- Have any of the staff ever questioned a decision made by another staff member, the organisation or a family member about something that affects the resident? What would happen if they did?
Further reading and other resources

- Leura Day Options DVD on Active Support on YouTube: [http://m.youtube.com/watch?v=X0ooynSSmU&feature=plcp](http://m.youtube.com/watch?v=X0ooynSSmU&feature=plcp)

References


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