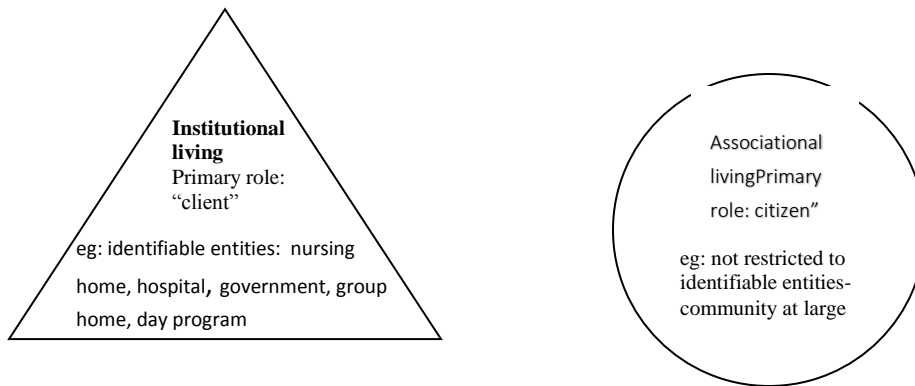


Understanding Institutional and Associational Living



Institutional Living Examples (primary role: client)

Institutions or formally structured organizations are at the centre, existing for the purpose of meeting identified needs. Sometimes one needs institutional type parameters to ensure standards of compliance and service, however, they do not apply to relational living

1) Institutional Trait: Organization is the focal point, accepting eligible "clients" into their readily identifiable service structure based on needs (eg, hospitals, nursing homes, lodges, shelters, etc.). Language speaks to number of "beds" and "clients" living there. Control of the setting rests with staff. Focus on safety and compliance

Specific- In a home shared by two young women, staff tell us that the other "client" versus "roommate" is out. Strong agency presence-lots of signage, binders and staff office, while lacking in comfort or personalization of home for people who lived there

Specific- One home had a big white board adorning a dining room wall, identifying the residents by name, date of birth and PDD number

2) Institutional Trait: Individuals come to the setting for the primary purpose of addressing an assessed need, which the organization is designed to meet- nursing home care, day programming, etc. Program plans are in place, binders abound and the focus is on behavioural management

Specific- When surveyor was making small talk with the interviewee who she knew socially, staff walked in and stated that the man has "behaviours" then walked away. Privacy was not respected and all were embarrassed.

Specific- One home's front entry had large signs of agency's mission and values as décor. It also had thin, inexpensive curtains covering a dirty picture window. The juvenile hot pink curtains were covered with stars, hearts and polka dots. The residents of this home were all young men.

Specific- In the above home, people were frequently walking in and out of the home. Each time an alarm beeped and an announcement made "Door open". Nobody seemed to take notice of this and nobody checked the door to see if there was an issue.

3) **Institutional Trait:** Safety and organizational standards are central issue

Examples

Specific- house floorplan is prominently posted, fire extinguisher is featured, with a big red arrow posted beside it and staff schedules are posted

Specific- upon entering specific agency run homes, guests are immediately informed about fire exits, safety concerns, location of phones and need to sign an informed consent form. Only then are they introduced to the person being interviewed.

4) **Institutional Trait:** Focus of the organization is centered on deficits and needs, which are to be addressed by staff

Examples

Specific- Three elderly women who share a home, have personalized childlike charts posted, tracking their behaviour towards goals, using stars. Charts from the previous month were still on walls and showed few stars

Specific- During one interview and in front of the person being interviewed, a support staff openly shared that the woman was tense as she just came back from her psychiatric appointment

Specific- In one home staff made a psychiatric referral while the My Life team leader sat nearby. The team leader was able to hear personal details of the person, condition and behavioural concerns.

5) **Institutional Trait:** Structured staffing ratios, with staff always present when “clients” are there

Examples

Specific- When ill, people can't leave their day program if there is no group home staff to let them in. This causes tension between the day program and group home which should be working in concert

Specific- staff turned surveyors away from homes at designated interview time, citing the home being closed for business because at dinnertime.

6) **Institutional Trait:** Organizational hierarchy is in place. Care and control of the environment rests with staff, not the people who call the setting “home”.

Specific- When staff are unaware of our team's scheduled visit, they routinely call their superior to confirm the team's validity, despite our team having identification, agency schedule, signed consents, etc. Staff do not ask the interviewee if he/she is aware of the visit.

7) **Institutional Trait:** Administrative rules dominate

Examples

Specific- Staff extend a guest book for signing, even before team members have the chance to remove footwear at the door.

Specific- People who reluctantly agree to be interviewed often share that the staff tell them that it is mandatory

8) Institutional Trait: Entrance criteria exist. Diagnostic criteria must be met to qualify for support services

Specific- One “behavioural” home exuded institutionalization in signage, décor and security features. One young man said he would never have friends over as he didn’t want anyone to know where he lived.

Specific- One man stated that he was bored at his day program. He noted that he’d been served by the agency since he started school at age 5. He had been attending programming at the same agency run building for 48 years.

9) Institutional Trait: Focus on specialization and segregation, based on defined need of identified deficits and limitations of the clientele

Specific- In a day program a person was observed playing a solo game of virtual bowling, aiming at a screen with cartoon figures. Other people in the room were totally disengaged from the activity.

Specific- In another, adult participants were provided with childlike stimulation. One man coloured was in a “Baby Toys” colouring book, while a woman chose an infant stimulation toy from the toy box.

10) Institutional Trait: Often viewed as unique communities within the broader community. Group homes are integrated vs included in community and are often readily identifiable on residential streets.

Specific- Group homes are routinely recognizable on the street. Many stand out for neglected home maintenance, lack of landscaping and heavy reliance on street parking for staff which creates parking issues for neighbours

Specific- In a group home there was décor on the walls, but it was childlike, including My Little Pony and ballerina decals. In the same home a senior citizen’s hot pick room was filled with toys for a young girl, including a collection of huggable dolls in highchairs.

11) Institutional Trait: Care and control rests with the staff, with these few people being in a position of power over the larger group of clientele.

Specific- It is commonplace for staff to have keys to homes where they work, while the residents who live there do not. As well, staff wear shoes in the home and tell guests to do the same, but all residents are in sock feet.

Specific- In one group home a person wanted a drink prior to doing the interview. The staff was adamant that he must do the survey first, even though he said he was really thirsty and our team did not mind. When he asked again he was told that if he persisted he wouldn’t get any at all.

Association Living Examples (Primary role: citizen)

Associational community living is about diversity, reciprocity and acceptance within the fabric of our communities. As this is about people being recognized as contributing members of the community, the setting is not relevant.

1) **Associational Trait:** Person is the focal point, not as a “client” but as a valued citizen with unique gifts

Example:

When a woman found it too stressful to complete a survey so became unresponsive, staff provided an empathetic proxy response. Throughout the survey, the staff respectfully engaged the person and maintained eye contact, while gently massaging the woman’s hands. The woman became calm and the staff ensured she remained the focal point of the interview.

2 **Associational Trait:** Individuals do not need to meet set eligibility requirements to be part of associational living

Example: During a proxy interview, a dad learned that his son did not have a key to his support home. As his son regularly misplaces things, the man understood the rationale, while being concerned that his son could not gain entry if nobody was home. He quickly decided to invest in an electronic door code as his son readily retains numbers. This way his son has more independence, the family’s security is maintained and the code fits with a community trend.

3) **Associational Trait:** Unpaid relationships are central in the person’s life, with any service component being supplemental and focused on assisting the person to be involved and contributing

Example: One young man with significant challenges is a long-time member of a local karate school, where he is naturally supported and challenged by fellow students. After class he catches a lift from fellow students for their weekly pub visit. Staff drop him off at the school before class and pick him up after beers at the pub.

4 **Associational Trait:** Focus is on the individual’s contributions and capacity, with PDD funded staff available in supportive capacities, with an emphasis on flexibility, responsiveness

Example: Sometimes staff had excellent relationships with individuals and were very helpful to the interviewing process. In one interview, the staff actively engaged an extremely reticent individual. Using humour and great sensitivity he supported the person to proudly complete a supported self-report, rather than do a proxy interview on the man’s behalf.

5) **Associational Trait:** *Primary* goal for paid staff is to support capacity and promote community inclusion, not the provision of paid care within the setting

Example: One agency had a distinct welcoming feel, with places for people to hang out, grab a coffee, watch tv or check email. The environment was inviting with nice artwork and comfortable couches. Interactions were particularly relaxed, familiar and extremely respectful, with no clear delineation between staff and those being supported. On initial contact it was often a challenge to identify who was staff and who was being supported.

6) **Associational Trait:** Focus on the promotion of inclusion, versus adhering to safety and organizational standards

Example: In one small community an older man receives supports in a very fluid manner. His long-term relaxed lifestyle and seasonal pursuits are well understood and respected. No safety and organizational standards are imposed by the agency, while always being willing and able to support as needed. He is welcomed when he drops by the office, is engaged when seen in town and checked on if not seen for awhile.

7) **Associational Trait:** People are viewed as living in typical home settings in the community, not as living in residences where people are cared for

Example: One young man shared condo living with his paid supportive roommate, with whom he shared duties, responsibilities and life. The condo was comfortable and lived in, reflecting the interests of both men. When the young man being supported wanted to adopt a family member's cat, the cat simply became a new and welcomed member of the household.

8) **Associational Trait:** Community participation activities reflects the experiences shared by the general population based on interests, not scheduled outings or specialized needs

Example: A husband and wife focus on what community events provide opportunities based on their interest. They are routinely out and about engaging with fellow citizens. This includes participating in a wide variety of events, including volunteering at festivals, attending fun events, supporting rallies of interest, etc.

9) **Associational Trait:** Voluntary associations are the focal point, with individuals coming together as citizens, based on interests, desires, contributions and capacities

Example: Someone with significant physical, behavioural and emotional challenges has historically found it hard to find and maintain stable housing. With a focus on citizenship, an agency has helped him find a landlord who accepts his challenges, while valuing his contributions and capacity. The landlord has invested emotionally and financially, to promote the person's safety, comfort and stability.

10) **Associational Trait:** Individuals and families choose from all the community has to offer and determine the nature of the associations, rather than choosing from within set organizational choices and what spaces are available

Example: One family's son had always been assessed in a negative light by agencies as having high needs. Wanting to focus on capacity and inclusion they explored other options. They bought a condo and started with paid roommates. He later progressed to living alone, with no overnight support. He works, actively pursues community interests and stays close with his family.

11) **Associational Trait:** Individualization, flexibility, self-determination and inclusion are key

Example: When a woman with complex needs became hyper-focused on wanting to keep a visitor's bracelet, a skilled staff expertly intervened. She calmly acknowledged the woman's

desires, gently introduced other perspectives, explored options and always offered choices. Ultimately this allowed the woman to make a well informed decision and the situation was resolved with dignity.

12) **Associational Trait:** Focus is on contribution to society in valued social roles, eg employee, volunteer, neighbour, artist, etc.

Example: Individuals who attend a drop in art program have their art framed and for sale in the art gallery at competitive prices