

JRB ASSOCIATES
JACKSON LONGITUDINAL STUDY
CONTEXTUAL OBSERVATIONS AS INDICATORS OF QUALITY OF LIFE
AND QUALITY OF CARE

OBSERVER S GUIDE
FOR CONDUCTING AND RECORDING ON SITE OBSERVATIONS DURING THE
DATA COLLECTION PROCESS

1 Because of scheduling requirements the data collection process and particularly the observation of the movers in their residential settings will not be as informal or relaxed as optimal. Rather because appointments will be set in advance both the mover and others (staff family or other residents) may prepare for the interviewer/observer's visit. Nevertheless we believe it is possible to collect accurate and reliable data from field visits to the movers. The instructions provided below are intended to keep the observations as naturalistic as possible.

2 The contextual observations should be made simultaneously with the in person survey. But the data from these observations should be recorded after the interviewer is finished with the in person interview. This will give the interviewer the opportunity to reflect and also to provide complete attention to the mover during the interview process. Although *observation* is the primary mode of data collection some data (as noted in the instrument) will be gathered by asking questions of staff members.

3 If the individual is not verbal the interviewer should pay special attention to the observational data collection process. In these instances the quality of care observational data will serve as an important proxy for the in-person interview data. Appropriate modifications (for example spending more time observing the environment interactions and behaviors) will be required and these decisions must rest with the interviewer. It is critical that these data collection choices be recorded on the interview/observation instruments or in field notes so the researchers can appropriately account for the changes. This will help control for variance and possible sources of contamination.

4 Confidentiality of **the data**. If staff members or others request a copy of the survey please refer them to JRB Associates. We cannot give out any raw data in the field! This is especially important in light of the Jackson Class lawsuit.

5 Definitions. The following definitions focus on the specific areas of observation and are intended to reduce subjectivity in coding the data. For most areas of observation three choices are provided definitions are given for the mid-point response. (Exceptions are noted with the definitions below) Significant deviations on either side of the mid point would be coded by selecting either end point. Additional notes should be provided whenever an exceptional (either high or low) response is given or whenever comments might prove useful in providing an overall picture of the quality of care.

PHYSICAL SETTING

Q1 Is the home in a safe neighborhood?

Safe = The neighborhood is routinely recognized by individuals living in the residence as being safe and you would personally feel comfortable being on the grounds and on the surrounding streets and in the general area.

Q2 Is the home maintained?

Maintained = The residence is similar in maintenance to the surrounding homes and buildings in the immediate neighborhood the yard is mowed (if grass exists) and things are reasonably orderly the home itself is in reasonable repair. No major maintenance problems exist.

Q3 Is the home a barrier-free environment? (End-point is defined)

Barrier free environment = All barriers to daily independent living of the subject are removed For illustration purposes there might be push button flush toilets water dispensers for getting drinks push button sinks large showers with seating The grounds are easily reached and can be negotiated independently The special modifications are discreet and well designed

The phrase for the individual is critical The question is not about legal requirements but adaptation for the mover's needs For example if the person uses a walker with wheels do the floor materials inhibit the movement of the wheels? Observing the person in the environment provides the surest basis for assessment

Q4 What is the condition of the furnishings?

Good condition = Furnishings are undamaged clean and are in minimal need of repairs or replacement The carpets and/or other floor coverings are reasonably clean and do not require replacement or major repairs All major appliances seem to be functioning well All lights and electrical fixtures seem to be operable The question does not ask your judgment regarding the attractiveness or tastefulness of the furnishings!

Q5 Is the residence large enough to accommodate those living in it?

Good space = The space reasonably accommodates the number of people living in it there is adequate space for personal belongings Take into account all the residents special needs Requirements for 3 people using wheelchairs sharing a space may differ from those of 2 ambulatory people and one using a chair

Q6 Other physical characteristics:

Adequate (6 1-6 3) = Connotes a reasonable quantity or quality of the physical characteristic under observation which would be likely to be confirmed by a majority of people observing the phenomena It does not mean ideal in terms of the observer's preference The *windows* item concerns the availability of natural light which is at a premium for people who spend much of their time indoors since it may significantly affect mood

Uncomfortable (6 4) = Much too cold (< 60) or hot (> 80) **Q7 Food**

tastes good looks good and appears healthful

Marginal = The food does not look appetizing food seems to lack nutrition and balance the food tastes or smells bad

The observer should consider that food preferences vary among cultures as among individuals and should avoid projecting her own tastes in this area

Q8 Is the home secure?

Acceptably secure = There is a system to monitor the flow of traffic in and out of the home there is a window or other means to see who is at the door prior to opening it each door to the outside has a lock on it all windows have locks that seem to operate curtains drapes or blinds are present and they operate properly there are adequate lights on the property safety check lists are present shrubbery is trimmed for easy visibility

Q9 There is easy physical access to the community?

Acceptable physical access - Transportation is available or easily coordinated information about community activities is displayed staff are available to coordinate transportation to and from community events the individual has adequate adaptive equipment to enable her/him to move easily into the community

These are independent aspects of the question of access which is about whether the individual has the means to easily get to and participate in events and activities outside the home Easy accessibility will mean different things to different people For instance public or private wheelchair accessible transportation may be available but the individual's wheelchair may be of a nonconventional design that doesn't fit on the vehicle In such a case access to the community would be *unacceptable* If the individual uses a more conventional wheelchair which allows her to attend such activities but doesn't accommodate her physical needs possibly causing discomfort access would be *marginal*

Having to plan transportation several days in advance also provides only marginal access to the community

STAFF AND QUALITY OF CARE:

Q10 [Not coded]

Q10 1 Staff members speak in an assertive respectful tone

Q10 2 Verbal communication is congruent with their body language

Usually = Approximately 80% of the time (i.e. most of the time with occasional lapses which are noted and corrected)

Assertive here means direct honest and respectful of themselves and others Therefore a patronizing infantilizing or authoritarian tone would not be respectful Affectionate names (like 'Eddie baby') should not be considered infantilizing if accompanied by otherwise respectful and assertive behavior

The second part of this question draws attention to the fact that we also communicate attitudes non verbally The observer should attend to whether what the staff person is saying matches the way she or he is acting

Q11 Staff members are clean and have no signs of illness

Acceptable = Staff members appear healthy no obvious signs of illness staff clothing is clean and does not have an odor

Unacceptable = Staff person looks dirty or smells unwashed clothes worn by the staff are dirty or torn staff person shows signs of ill health
(End-points defined marginal may indicate suspected temporary phenomenon eg a staff member may have a cold)

Q12 Staff members are knowledgeable about the health and medical needs of the individuals living there

Acceptable = There is an accessible cover sheet summarizing daily health needs for each individual all staff can generally describe special diets medications and adaptive behaviors

REGARD FOR THE INDIVIDUAL

Q13 Individual looks good in her or his clothing (End-points are defined)

Acceptable = Clothes and shoes are clean fit well and are in good condition there are choices for all seasons individuals own their own clothes and the clothing is varied

Unacceptable = Clothes are not well cared for shoes are in ill repair or do not fit clothes do not fit or are obviously unclean; individuals must share clothing

Q14 Individual has a clean appearance (End-points defined)

Acceptable = Hair is well kept; nails are clean skin conditions are treated individual has a generally clean appearance

Unacceptable = The individual is dirty or smells bad hair is unwashed uncombed nails are dirty skin conditions are unattended

Q15 Individual has her/his own private space and property

Acceptable = The individual has enough space to keep personal possessions personal property is kept in good working order personal effects reflect the individual's interests The absence of personal effects should be noted

The individual's degree of *control* over personal property may be relevant in some living situations The individual's ability to ensure that her/his space is not intruded on and that property is both secure from theft and accessible to the individual are important dimensions of privacy

Q16 Opportunity to make choices

Acceptable = The individual has choices throughout the day and in all areas of living including planning meals selecting types of food deciding what to eat choosing clothes to wear choosing how to spend unstructured time deciding when to go to bed at night Opportunities to practice meaningful choice making are presented in ways that are sensitive to differences in individuals expressive communication ability

The key issue here is whether the choices offered are *meaningful to the individual* The observer must take into account the individual's ability to express or indicate preferences The breadth of the choices offered may vary and choices may be more substantial for individuals who function at higher cognitive and expressive levels The appropriateness of the choices offered must be assessed in light of these factors If the individual expresses little or no preference try to discover whether

- (1) staff provide a variety of experiences in the choices *they* make for the individual (e.g. trying new foods introducing new activities going to new places) or
- (2) staff stick to the same routines without variation day to day or week to week and
- (3) staff are attuned to how the individual is responding to the choices staff make

If an individual is given only the choice of A or B when other options exist *for that person* the choice offered may be less than acceptable To be acceptable choices offered should not be merely formal but substantive in matters related to the person's life — such as roommates residential location work and leisure involvement

Q17 Friends and social relations are encouraged and supported

Acceptable = individual participates in a variety of activities with able bodied and disabled individuals the individual has frequent opportunities to spend time with a friend staff provide regular and active assistance in developing and maintaining friendships staff actively facilitate social relationships by structuring regular social activities staff help the individual learn and practice good social behaviors If the individual doesn't have any friends does staff engage him/her in activities with other people?

PERSONAL GROWTH HEALTH AND SAFETY:

Q18 The individual has necessary adaptive equipment to move around her/his home and community

Acceptable = The individual has access at all times to adaptive equipment and knows how to operate it staff work with the individual in building more competence in using adaptive equipment the condition use and fit of adaptive equipment are examined periodically

The observer should pay attention to whether the individual is able to use the adaptive equipment successfully throughout the range of environments encountered within the residence

Q19 The individual receives information to encourage personal well-being

Acceptable = Potential health problems are recognized and addressed with the individual staff support the individual in daily choices to apply wellness information rights of non smokers are protected opportunities exist for individually based exercise there is some discussion of good health practices

This information can be communicated in a variety of ways — eg through modeling prompting or verbally The observer should pay attention to the types of activities planned do they encourage personal well being?

Q20 Individual gets adequate medical attention based upon that person's individual needs (End points defined)

Acceptable = Individual has medical care through a personal physician a log of the individual's health care is maintained an individual who has an illness or other treatable health condition is currently receiving medical care

Unacceptable = Individual has no physician medical record keeping is absent or inadequate to enable staff to know individual's needs an illness is untreated

Q21 The individual receives adequate dental care (End-points defined)

Acceptable = The individual has a dentist teeth are cleaned and checked on a regular schedule as appropriate all dental needs are met

Unacceptable = The individual has no dentist individual is not scheduled for regular dental care existing dental problems are not treated

Q22 Plans and procedures (End-points defined)

Acceptable = Plans or procedures are written and adequately detailed to be a basis for action staff are able to describe how the plan is implemented

Unacceptable = Plans/procedures are not written are unavailable or obviously not used as a guide to action staff are unaware of their existence or unable to describe how they are used

The observer should ask staff about plans and procedures Can they recite or discuss them knowledgeably? If they need to look it up are written procedures close by and handy? Do staff use and follow them? A staff member's knowledge of these resources may be ascertained by asking If you are unsure of how to proceed with this person in a given situation how would you get more information?

23. Other Observations.

These should include any significant factor related to an individual's living arrangements that may affect her/his quality of life which may be difficult to quantify or to "fit" on any of the scales above. "Helper's" observations *about* a client made during the interview stage which reflect the helper's viewpoint (rather than the client's) should be noted here if significant. Observations may relate to such issues as:

- ? whether specific aspects of the environment reflect an "institutional" or "home-like" atmosphere;
- ? observed self-injurious, aggressive or other behavior that may affect the person's quality of life (such as sexual behaviors or reactions to them that may limit community access, or impair interactions with peers and/or staff);
- ? incongruities between medical diagnosis and the observed state of the client's well-being;
- ? the impact of staff and others on the client's quality of life, etc.